THE DISABILITY HANDBOOK

A Handbook on the Care Needs and Mobility Requirements likely to arise from various Disabilities and Chronic Illnesses

Second Edition

Compiled and Edited by:
Dr Mansel Aylward, Dr Peter Dewis & Dr Moira Henderson

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First Edition 1992

PREFACE TO THE SECOND EDITION

The first edition of the Disability Handbook was written in preparation for the introduction of Disability Living Allowance and Attendance Allowance for the over 65s (DLA/AA) in 1992. DLA brought in some major policy changes in the field of benefits for sick and disabled people. Notably, adjudication became the responsibility of non-medical adjudication officers. The Handbook was designed to be a source of reliable information on the care and mobility needs likely to arise from a range of medical conditions. Although written primarily to help adjudication officers, it was hoped that it would also be of assistance to all those involved with DLA/AA, both inside and outside the Department. Happily, this has turned out to be the case: it is extensively used by members of Disability Appeal Tribunals, as well as by adjudication officers.

It was always intended that the Handbook should be a living document and over the years, a number of amendments and additions have been produced in the form of annexes to the original text. It has become clear that this was making the book rather unwieldy and that the time had come to produce a new edition. In compiling this, we have been able to draw on the accumulated experience of people, too numerous to mention, who have been involved in DLA/AA since its inception. We have also tried to incorporate all the latest developments in the medical and disability fields. It is a testament to the success of the first edition that we have been able to leave much of the original text unaltered.

It has to be remembered that the primary purpose of the Handbook remains unchanged and consequently the Introduction to the first edition appears in its original, unaltered form. We hope that, through this new edition, the Handbook will be able to continue to fulfil its unique role in the field of disability assessment.

Peter Dewis
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LONDON May 1998

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1. INTRODUCTION TO THE FIRST EDITION

1.1 Aims of the Handbook

1.1.1 Disability Living Allowance (DLA) and Attendance Allowance (AA) are benefits payable to people who have significant problems with personal care and/or with mobility because of long-term severe physical or mental disability and to those who are terminally ill. Many different medical conditions and developmental abnormalities give rise to such problems. This handbook is intended to provide for all who are involved with these benefits an authoritative source of information on the likely effects that the more commonly occurring conditions have on a person's care and/or mobility needs. The handbook provides *general* information about these conditions only. As such it is not intended to be used in preference to evidence available in individual cases, as conditions do affect different people in different ways. The purpose of this handbook is merely to provide a point of reference for those working on DLA and AA, against which to compare such evidence. If there is a considerable difference between the information in the Handbook and the evidence which has been supplied then the Adjudication Officer (AO) may wish to consider seeking further evidence before reaching a decision.

1.1.2 The handbook has been written by medical staff of the Department of Social Security with advice from the Disability Living Allowance Advisory Board (DLAAB) and contributions from many organisations representing people with disabilities. The Benefits Agency Medical Services together with the DLAAB will continue to monitor the information contained in the handbook and will make amendments and/or alterations as new conditions or treatments emerge.

1.1.3 This is not a medical textbook. Adjudication Officers are not medically qualified. Most people involved with the care of people with disabilities have no medical training or background. For these people, a medical textbook would be of no help to their understanding of the care and mobility needs of the people they are dealing with. This handbook is written with this in mind. It contains the minimum of medical terminology so that it can be readily understood by all concerned. Where medical terms cannot be avoided they are either explained in the text, if this does not disturb its flow, or are included in a glossary of terms.

1.2 Type of information included in the handbook

1.2.1 This handbook provides information on many illnesses, diseases and disorders that may give rise to long-term disabilities and to the need for palliative care. It describes, in general terms, the effects of these conditions and the care and mobility needs that can arise from them. For each of these conditions the handbook gives:

(i) a general description of the medical condition, its clinical characteristics and the disabilities which may arise from it;

(ii) an explanation of the likely effects in terms of care and mobility needs;

(iii) an indication of the likely duration of such need, and,

(iv) sources of further information which may be sought in individual cases which require clarification or amplification.

1.2.2 This handbook contains no advice or guidance on the level of award that should be made. That is a decision for the Adjudicating Authorities alone on the basis of the evidence available in an individual case. The handbook refers only to the likely effects of the conditions described and the care and mobility needs that may generally be expected reasonably to arise from them.

1.3 Target audience for the handbook

1.3.1 The handbook is intended primarily to help Adjudicating Authorities to assess the medical evidence that is presented to them when a claim is made. It is aimed particularly at the Adjudication Officers who decide claims and reviews but it will be available for use by anyone else who wishes to refer to it. As independent statutory authorities Adjudication Officers are at liberty to use whatever source of information they feel appropriate when deciding a claim.

1.3.2 The handbook is also intended to be used by the medical staff of the Benefits Agency Medical Services (BAMS) who may be called upon to give advice to the Adjudicating Officers and to the presenting officers at Tribunal hearings. Not all claims are likely to present a clear picture of the person's care and mobility needs. Not all conditions which may give rise to claims are covered by the handbook; selection has been based on those illnesses and disabilities which occur most commonly or are likely to pose special difficulties in defining the spectrum of care and mobility needs to which they give rise. The handbook and the general principles which underpin it will also assist the Benefits Agency Medical Services Staff in providing consistent and authoritative advice on the effects of disabilities as they relate to the need for care and their effects on walking and other mobility considerations.

1.4 Organisation

1.4.1 The handbook is divided into two principal sections, dealing with disabilities affecting adults [Chapters 3-32] and children [Chapters 33-50], with a final Chapter [45] on Malignant Diseases. For a child the effects of disability arising from a particular condition can be very different from those experienced by an adult. The emphasis of this handbook is on the effects of disability and so it is important to discuss separately the consequences of conditions that affect both children and adults.

1.4.2 Within each section, the chapters describe related conditions that have similar effects. This is to avoid unnecessary duplication of information. The order of the chapters is not significant. There is no distinction in the order between those conditions included because they are common and those conditions included because they may give rise to problems for adjudicators.

1.4.3 Each chapter is divided into sub-sections that give some background information on the conditions included, describe the effects of the disability and indicate the care and mobility needs that may arise. There is also a sub-section that discusses the likely duration of need and a sub-section on the most useful sources of additional information.

1.4.4 A glossary of medical conditions, technical phrases, commonly used Latin abbreviations and a comprehensive index are provided.

Mansel Aylward

November 1991

2. PRESENTATION OF DISABILITY

2.1 Contents **Paragraph**

2.2 Introduction

2.2.1 The handbook presents, in general terms, the care and mobility needs that can be expected to arise from different medical conditions. There is much confusion surrounding the use of terms such as impairment, disability, handicap and disablement. It is not the purpose of this book to go into detail in explaining their various meanings. However, it is important to understand that a disability refers to an inability to perform a particular activity or task and this (almost implies) a certain level of need. Fulfilling this need may require the assistance of another person. It is also important to recognise though that people with the same medical condition of a similar severity may have very different levels of disability and hence very different care and mobility needs. At one extreme a person will appear totally independent whilst another person may be very dependent upon help from others. There are clearly many factors, in addition to the nature and severity of the underlying medical condition, which interact to determine the overall level of disability and care and mobility needs.

2.2.2 A person's domestic circumstances such as the type and layout of accommodation, can also affect the apparent level of need. The presence or absence of a carer will greatly influence what a person has to do for themselves. A person who has no-one to help them may be forced to carry out tasks that should really be done for them. Many carers work very hard to make it appear that their relative or friend is independent but, in reality, much hard work continues "behind the scenes". On the other hand, understandably, some carers may be overprotective and give more help than is needed.

2.3 Underrepresentation of Disability

2.3.1 People are often reluctant to admit the extent of their disability, even to themselves - and it is natural that people are much more keen to talk about what they *can* do, rather than what they cannot. Some people, often because of their disability, may be unaware of its true level. This means that disability may be represented as less than might be expected. There are four main situations where this is likely to happen:

(i) Older people, and many people with disabilities, are fiercely independent and will not admit even to themselves the full extent of

their care and mobility needs. In this situation people will frequently try to do things that are beyond their capabilities. Their carers often feel that it is not safe to leave them on their own because of the fear of what they may try and do. The carer may well supply additional information with the claim or, indeed, they may submit the claim on behalf of the disabled person because they have refused to do it themselves, arguing that they do not consider themselves disabled.

(ii) Many people, particularly those with mental or learning disabilities do not appreciate their level of need. For these people, the carer or a closely involved professional will be able to give a more reliable picture of the true level of need.

(iii) Many people who live alone are forced to carry out day-to-day tasks that should, ideally, be done for them. When presenting their own evidence they are likely to report the situation as it is, not as it ought to be. In many such instances it may not be possible to get a true picture of the person's needs without additional reports from professionals.

(iv) Many carers, particularly those looking after people with severe learning disability, work extremely hard to make the disabled person appear as independent as possible. For example, they may work for months or even years to teach the person how to go to the local shop on their own. This independence is an illusion - any deviation from the "familiar" will expose the true extent of the continuing care and supervision being exercised in the background. These people only appear to function reasonably well because of the highly structured environment which has been created for them.

2.4 Overrepresentation of Disability

2.4.1 There are situations where disability may appear to be in excess of that expected. These are largely dealt with in Chapter 19. In addition, many carers feel very protective towards the person they are looking after and there is always the temptation to give more help than is needed. In the long run, this can be detrimental to the disabled person by preventing them from achieving whatever independence they might manage. Understandably, this may happen amongst parents of children with disabilities. Parents of healthy children often find it difficult to "let go" as the child grows up. The presence of severe disability in the child makes the process that much more difficult.

2.5 Interaction of Disabling Conditions

2.5.1 People may have more than one medical condition and the effect on overall disability can be very significant. Because of the interaction of different

conditions overall disability may be much greater than would be expected if each condition were considered individually.

2.5.2 The individual conditions themselves may not give rise to significant care or mobility needs, whereas their combined effect does. For example, a person with mild physical disability and mild to moderate learning difficulty may find it hard, because of the learning difficulty, to adapt to and cope with the physical disability; a person with visual impairment is more disabled if also deaf, and an independent wheelchair user will lose independence if arthritis develops in the upper limbs. When combined with the normal effects of ageing, even minor disabling conditions can give rise to care needs [see also Chapter 3].

2.6 The Effect of Chronic Pain

2.6.1 There may or may not be an obvious relationship between an injury/disease and chronic pain. The amount and quality of pain felt is influenced by a number of factors including physical and psychological ones and may be disproportionate to an actual injury or medical condition.

2.6.2 Tolerance and acceptance of pain varies from one person to another. Pain which to one person is mild can be unbearable to another and each person may be able to tolerate it better on some days than on others. It can become so intrusive that it leads to substantial disability which is far greater than the condition which may have caused it in the first place

2.6.3 Chronic pain can be demotivating and affect a person's ability to cope with even the simplest task, to take decisions or to plan activities. It can reduce a range of movement of which a person may otherwise be capable. It can affect sleep and cause depression and stress. A person may thus be less able to cope with the other disabling effects of an illness or condition if pain is present.

2.6.4 On the other hand pain, being impossible to measure scientifically and being invisible, can be exaggerated. Where pain is a significant feature of a person's claim, assessors should take the opportunity to discover its degree and quality as perceived by the sufferer and the effects it has on his/her daily life in order to determine the care and mobility requirements.

2.6.5 Various treatments are available for chronic pain. The most common is the use of pain killing drugs (analgesics), ranging from mild ones such as aspirin to strong ones such as morphine. Other forms of treatment include heat therapy, ultrasound treatment and transcutaneous nerve stimulation (TNS). Treatment may also include psychotherapy and counselling.

Treatment may be carried out at a Pain Clinic attached to a local hospital and may consist of a combination of therapies. The effectiveness of treatments vary according to the condition being treated and also from individual to individual. Sometimes chronic pain is intractable.

3. THE EFFECTS OF AGEING

3.1 Contents

3.2 Introduction

3.2.1 Throughout life changes to body tissues and organs are occurring which are not due to disease but are part of the normal ageing process. An example of one of the earliest obvious changes is the need for reading glasses in mid-life; as a result of age, changes occur within the lens of the eye so that the lens is less able to focus on near objects. As age increases, other changes gradually becomes more obvious. These may include difficulty hearing in a crowded room, change in gait, which becomes wider based with smaller steps and more unsteady, and difficulties in passing urine, for men, due to enlargement of a gland situated near the neck of the bladder (prostate gland).

3.2.2 Ageing changes alone may result in increased care or mobility needs. Disability which in a younger person would be of a minor nature, can become very significant in the presence of changes due to ageing. Ageing changes occur in bones and joints, and may result in osteoporosis (thinning of the bones) and osteoarthritis. Muscle power and strength are generally reduced. An important change which occurs with increasing age is a change in gait and balance. Elderly people tend to walk with short, shuffling steps, with less tendency to swing their arms

3.2.3 Hearing and vision decline with age. Many elderly people with hearing impairment have difficulty in understanding speech in noisy surroundings, or when speech is less distinct or delivered a little faster than usual. Glaucoma and cataracts occur more commonly in older people, and may impair vision.

3.2.4 Mental changes occur with increasing age. Elderly people have a slower reaction time and may be slow to grasp new ideas. They may have difficulty in remembering new information, ie impairment of short-term memory, making them appear forgetful.

3.2.5 Older people are also more likely than younger people to be affected by more than one disabling condition at a time, and the interaction of the various conditions will have to be taken into account in considering their care and/or mobility needs [See also Chapter 2.]. For example, the effects of congestive heart failure, for which the treatment is water tablets (diuretics), are much greater on someone who suffers from incontinence of urine; long-standing rheumatoid arthritis may be combined with peripheral vascular disease which may lead to a lower limb pain or amputation and causes much greater mobility problems than would either condition alone; poor sight and poor hearing are a common and very disabling combination.

3.2.6 The effects of ageing on a person who already has an existing disability can be greater than would normally be the case in a younger person. For example, arthritic changes due to age in the shoulders of a wheelchair user may cause a significant reduction in mobility and general independence.

3.3 Falling

3.3.1 Elderly people are more prone than younger ones to unpredictable, unexpected falls. The risk of falling increases with advancing age. Some falls are due purely to external factors such as loose floor rugs or uneven pavements. Such falls are unlikely to recur once the cause has been dealt with. Other falls are associated with risk factors (see below) affecting posture and balance; falls due to such factors are likely to recur. As the older person's reaction time and reflexes are slower, older people may be less able to save themselves when they trip.

3.3.2 There are many possible risk factors associated with falls. Each factor may be trivial in itself, but they are often found in combination; the more factors present, the greater the risk of falls. These factors may be identifiable physical or mental impairments. They may include disorders of the lower limbs such as osteoarthritis of the knees or problems with the feet, abnormalities of balance or gait, weakness of the limbs due to a stroke, or dementia. Other factors may not be readily classifiable as specific disease entities, but are general results of ageing. These may include impaired vision, generalised muscle weakness, and changes in the control of balance and posture leading to increasing difficulty in staying upright if challenged, eg if they encounter a loose mat, unlit stairs or uneven pavement.

3.3.3 The effects of medication can also put elderly people at risk. Sedative drugs, such as sleeping pills, are particularly important. Anti-depressants and sedatives may slow the reaction time and thus may prevent the older person from responding quickly or appropriately. Drugs which lower the

blood pressure, either intentionally, eg medication for high blood pressure, or as a side effect, eg water tablets (diuretics), may cause a fall in blood pressure on standing, making the elderly person feel dizzy, and falls may result.

3.3.4 Many elderly people have a significant number of these factors present, thus placing them at considerable risk of falls.

3.3.5 A fall affecting an elderly person is often more serious than a similar fall in a younger person. One in ten of all admissions to a department of geriatric medicine is as a direct result of a fall. Reaction time is slower in elderly people so they have less chance of breaking their fall, eg by putting out a hand, in such a way as to minimise injury. Bones become more brittle with age, so there is a much greater risk of fractures, particularly of the hip, pelvis, backbone (vertebrae), ribs, wrist, and upper arm. Bones are softer, due to the ageing change of osteoporosis and this also may result in fractures. It may take longer to recover from bruising and damage to joints. Loss of confidence occurs easily and it may take time for an elderly person to recover, putting their independence in jeopardy in the meantime.

3.3.6 An elderly person may have difficulty getting up after a fall. This may result in the person lying on the floor for a long period, and being at risk of hypothermia or dehydration, and delay in treating any injuries if help is not at hand.

3.3.7 Very elderly, frail people are generally at risk of unpredictable falls with possible serious consequences. If there are also identifiable specific risk factors, the danger of frequent falls increases still further. The risk increases with advancing age, as does the likelihood of a person needing help to get up after a fall.

3.4 Continence

3.4.1 Many elderly people have problems with disturbances of urinary function. They have to empty their bladders more frequently, and wake up in the night more often to pass urine, particularly men with enlargement of the prostate gland. In addition, they may suddenly feel the desire to pass urine but may be unable to get to the toilet in time, partly because the feelings occur so suddenly and also due to their slower mobility and possibly weakness of bladder muscles. The reasons for incontinence of urine are many, but the result is embarrassing and worrying and limits the ability to take an active part in life.

3.4.2 Incontinence of urine is far commoner in people with dementing illness and cerebrovascular disease as this causes interference with the brain control of urinary function.

3.4.3 Lack of control of bowel movements (faecal incontinence) also occurs in old age. Although less common than urinary incontinence, it is even more

embarrassing.

3.4.4 It is important to remember that many people suffering incontinence find it so embarrassing that they do their best to conceal the fact from relatives, their doctors and others who could help them to cope with it. The problem may not be mentioned on a claim form, or even to an Examining Medical Practitioner (EMP).

3.5 Mental Changes in Old Age

3.5.1 Just as physical functions are altered by ageing, so too are mental and intellectual processes. This may result in apparent changes in personality and in difficulty in remembering new information or recalling recent events. Also, the ability to solve problems and draw conclusions from information may decline with age, although experience which has accumulated over years remains.

3.5.2 Elderly people wish to be accurate in what they do, so it may appear that they are slower in performing tasks. In addition, their reaction time is slower as they are less "ready" to perform tasks and less able to perform several simultaneously.

3.5.3 Elderly people are able to remember basic new information such as names and addresses but may have more difficulty with factual information such as what is in the paper or on television. New information, such as a great grandchild's birthday, is more difficult to retain but there is no problem with long-term memory such as which school they attended or their own children's dates of birth

3.5.4 Personality may change with age. There may be a tendency to introspection and personality traits demonstrated in earlier life may become enhanced eg temper, prejudices etc. However, if there is a major personality change in old age, this may well be the result of a series of small strokes, a mental illness such as depression or a dementing illness.

3.5.5 The terms "senile" and "senility" may be encountered in medical descriptions of old people. These usually imply the kinds of changes discussed above, and do not necessarily indicate that the person is suffering from dementia.

3.6 Confusion

3.6.1 Often, elderly people are said to be "confused". This may be the result of many conditions, the commonest of which is dementia, but also including cerebrovascular disease, mental illness such as depression or anxiety and chronic diseases such as congestive heart failure.

3.6.2 The reasons why elderly people are said to be confused are many. It may be that the person asks the same questions many times because they have impairment of recent memory, making them forget that they have asked a question five minutes ago, so it is asked again. This can be wearing for carers. Also, they may have difficulty understanding questions put to them, and so may make inappropriate responses. Hearing difficulties will, of course, add to these problems.

3.6.3 The time of the day can create a problem for elderly people with a degree of dementia , and they may not know the day of the week, the month, or the year. Younger people often have a good idea of the time without looking at the clock but in older people, and especially those with a dementing illness, this ability may be lost. For some elderly people this can be severe enough to cause them to confuse day with night, and hence make phone calls to carers in the early hours of the morning, or they "wander" from home in the middle of the night.

3.6.4 For some elderly people the appearance of confusion is more marked at night. They may sleep poorly and become restless at night. Consequently, they are more difficult to deal with, especially if they feel it is time to get up and go to work. This is often very difficult and wearing for carers, causing them loss of sleep and anxiety which have long-term consequences for the caring process.

3.6.5 Dementia or cerebrovascular disease can cause disturbances other than loss of memory or weakness of limbs. People may lose the ability to perform certain tasks such as preparing a meal, using a teapot, using the gas stove or putting clothes on in the correct sequence, which makes them appear very muddled.

3.6.6 The elderly person with dementia, cerebrovascular disease or confusion stemming from chronic illness may have difficulty understanding words, reading words, speaking and producing words. Anxiety and depression cause problems with the ability to concentrate, perform tasks and retain information. Any of these disturbances may present as general "confusion".

3.6.7 A very important cause of confusion is the true acute confusion (ie. of sudden onset) which occurs not uncommonly in elderly people as a result of a sudden illness such as a heart attack, pneumonia, bladder infection or stroke, or in response to medication. The sudden onset of confusion, with agitation, restlessness and the appearance of being muddled is a very important sign in elderly people which usually means that they have an acute illness requiring investigation.

3.6.8 Elderly people with memory loss may give plausible accounts of events,

since they truly believe they have no problems and can perform all tasks. Some elderly people may appreciate that they cannot do so, but they still retain the ability to "cover up". For this reason, there is often a need to obtain further evidence if the situation is unclear.

3.7 Care Needs

3.7.1 Elderly persons may need attention in connection with personal care or safety purely as a result of changes due to ageing, as described above. The likelihood of this being so increases with advancing years. The presence of other illnesses or disabilities will increase the need for care. Because of interaction between any disability and the changes of ageing, care is more likely to be needed by the elderly than by younger persons with the same type and level of disability.

3.7.2 The mental changes due to ageing, combined with other disorders, including mental health problems may mean that elderly people require supervision to prevent them from coming to harm by day or night or both; or attention to remind them to get up, wash, dress, eat meals etc.

3.7.3 Falls occur more frequently in elderly people than in younger ones, and they find it very difficult to get up without help. If assistance is not available they may lie for long periods, risking hypothermia and dehydration.

3.8 Duration of Needs

3.8.1 Needs arising in elderly people are likely to persist and increase with advancing age.

3.8.2 Even those which arise as a result of an acute episode, such as a stroke, a heart attack or pneumonia, will last longer than in younger people and may be lifelong, due to the problems of adaptation and rehabilitation in this age group.

3.9 Further Evidence

3.9.1 Needs in elderly people are often self-evident. However, some old people are extremely proud and independent and have a great ability to understate problems. This may be intentional, because they feel their problems are due to their age and therefore they should just "get on with things" or it may be due to dementia or an acute confusional state.

3.9.2 Further information may well be required and it may be obtained from the carer, GP, social or welfare worker, staff in a residential home, day centre

manager, physiotherapist, occupational therapist or hospital specialist. If there is uncertainty about an elderly person's mental state, an examining medical practitioner (EMP) can be asked specifically to assess mental function.

4. FALLING

4.1 Contents

4.2 Introduction

4.2.1 There are certain disabilities which place the affected person at risk of falling. The nature of the disability and the person's age will have an effect on the amount of supervision they will need. In some cases, reasonable precautions can be taken which may avoid the risk of falling, or reduce the risk of injuries resulting from a fall.

4.2.2 There are six factors which are most important in determining the likelihood of falls occurring and influencing the risks of danger posed should one occur. These are:-

(i) the clinical basis for the falls;
(ii) the pattern of their occurrence;
(iii) the person's ability to take reasonable precautions to avoid them;
(iv) the age of the person;
(v) the ability of the person to get up unaided after a fall; and
(vi) the existence of another medical condition which would make falls more dangerous, such as osteogenesis imperfecta [see Chapter 46] or osteoporosis [see Chapter 6].

4.3 The Clinical Basis of Falls

4.3.1 A history of falls must have an adequate clinical basis. This is often provided by medical conditions which cause weakness, spasticity, or rigidity in the lower limbs or trunk, ataxia (incoordination of movements), involuntary movements, visual impairment [see Chapters 10 and 39], and confusion or disorientation [see also Chapter 21]. Without a clinical basis it is difficult to establish the cause of the falls.

4.3.2 In some cases there is no history of falls but a claim is made on the basis that, because of the clinical condition, the person might fall. Generalisations about risk of falling in certain clinical conditions are insufficient to establish need; it is the risk in the individual person that has to be assessed.

4.3.3 In the case of elderly people, falls may occur without there being any

readily classifiable clinical disorder though the elderly person often exhibits an unsteady or shuffling, short-stepped gait. Moreover, there are a wide range of conditions, which in elderly people may lead to a risk of falling even when only relatively trivial physical signs are detected on examination eg. osteoarthritis of the knees. Many elderly people may have great difficulty getting up after a fall without the help of another person and consequently find themselves at risk of developing hypothermia or dehydration. All these factors may influence the liability to fall and the occurrence of any dangers thereby arising. [See also Chapter 3]

4.3.4 The age of the claimant is also relevant in that falls in younger people, even those with disabilities, are less likely to result in significant injury than is the case in older people. Quicker reaction time may often enable a younger disabled person to take some protective action to minimise injury from a fall. Each case should be judged on an individual basis.

4.4 The Pattern of Falls and Their Predictability

4.4.1 The pattern of falls is important. If there is a history of one or two falls more than a year previously, there is unlikely to be an ongoing risk of substantial danger. Likewise, if falls only occur when the person first rises from bed or from a chair (commonly due to a transient fall in blood pressure), pausing for a few moments may remove the danger. But if falls are currently occurring unpredictably, the question of danger does arise.

4.4.2 Some practical precautions may have been taken to remove the risk of falling. Whilst it is reasonable to expect a disabled person not to undertake activities such as reaching for objects from high shelves, it is unreasonable to expect him/her to spend the whole day sitting in a chair. In addition many practical measures may reduce the risk of falling. If a mentally competent person is experiencing falls for which there is a clinical basis and reasonable precautions have not removed the risk of danger, then they are likely to need supervision and/or attention by day. Moreover the nature, pattern and frequency of falls in this circumstance will have an effect on the person's walking ability.

4.4.3 If the mental state is such that the person is unaware of potential danger and hence cannot take reasonable precautions; and the person is currently experiencing falls for which there is a clinical basis, there may well be a need for supervision during day-time.

4.5 Falls at Night

4.5.1 A risk of falling at night can only occur if the person gets out of bed and

moves around. The necessity for this may have been avoided by use of a urinal in bed or a commode beside the bed. Falls at night are most unlikely in these circumstances. However, the very elderly person may find it difficult to use a urinal in bed or may get out of bed for other reasons.

4.6 Further Evidence

4.6.1 In many cases a report provided by a GP or an examining medical practitioner (EMP) will assist in determining the risks arising from falls. This report should include a detailed description of the clinical condition and mental state of the person, a description of the pattern of the falls including the time and circumstances of their occurrence and a record of the severity of any injuries which may have been sustained. It may also help to determine what precautions have been taken to avoid falls. Simple statements such as "danger of falling" do not help in identifying the precise risks in any particular case.

5. PARALYSIS

5.1 Contents **Paragraph**

5.2 Introduction

5.2.1 Paralysis is the loss or impairment of movement due to damage in the nervous system or muscles, and may be associated with loss of sensation (feeling). Paralysis may occur following damage to the brain, spinal cord, nerves or muscles. Various terms are used to indicate the pattern of paralysis such as hemiplegia for one side of the body, paraplegia for both legs, and quadriplegia or tetraplegia for all four limbs.

5.2.2 The effects of damage to the brain and spinal cord will differ according to the site and level of damage. These include the loss of voluntary movement, an alteration in muscle tone (either relaxation or stiffening) and an alteration in reflexes. Not all of these are necessarily present, but paralysis is more than just a loss of power.

5.2.3 In most cases paralysis leads to a major disability, but the degree of disability depends on the site and extent of damage to the nervous system. Where there is a loss of sensation, there is the risk that at the affected part of the body there may be damage to the skin and the development of pressure sores. Other complications following damage to the spinal cord may also be present [see Chapter 18]; loss of bowel or bladder control will have both serious physical and psychological effects unless appropriately managed.

5.3 Care Needs

5.3.1 The degree of care needed depends on the degree of paralysis and which parts of the body are affected. Thus the person with paralysis may need no help, or may need help in attending to bodily functions (including toilet needs), sitting up in bed, dressing and undressing.

5.3.2 The person with paralysis may be unable to relieve sitting pressure during

the day, or turn over in bed at night. Attention may therefore be required to avoid the breakdown of skin and the formation of pressure sores, which can be serious problems.

5.4 Mobility Considerations

5.4.1 The mobility needs resulting from paralysis are very variable. At one extreme some people can manage to walk well, maybe with the aid of a walking stick, and at the other extreme some people are confined to wheelchairs, being unable to walk at all.

5.5 Duration of Needs

5.5.1 The duration of the needs varies considerably, depending on the degree and nature of the paralysis, and which parts of the body are affected. For example many people with strokes make a reasonable recovery and may become independent, whilst some people will be permanently disabled and always need assistance.

5.6 Further Evidence

5.6.1 If there is difficulty in deciding the degree of a person's disability and the amount of attention or supervision required, a report from a GP or an examining medical practitioner (EMP) should be obtained.

6. ARTHRITIS, RHEUMATISM, MUSCULO-SKELETAL AND RHEUMATOLOGICAL DISORDERS

6.1 Contents

6.2 Introduction

6.2.1 Arthritis and the rheumatic conditions constitute the major cause of chronic disability in the United Kingdom. They affect 10 million people including 1.2 million under 45 and 30,000 children.

6.2.2 **Arthritis** means inflammation in one or more joints. Movement in the joint is restricted with pain and swelling. The most common types are **osteoarthritis** (also known as **osteoarthrosis**) and **rheumatoid arthritis**. **Ankylosing spondylitis** and **juvenile chronic arthritis** (**Stills disease**) are other types of arthritis. Arthritis may also be found in other disorders (eg psoriasis, colitis, some infections and gout).

6.2.3 The **musculoskeletal** system refers to the bones of the body, the joints which link them, and the related structures such as tendons, ligaments and muscles. Musculo-skeletal disorders are therefore all those medical conditions which involve these parts of the body.

6.2.4 **Rheumatism** is a term often used to describe the great number of disorders

which affect the musculo-skeletal system. Furthermore a number of other terms are used to describe joint/muscle disorders eg **"frozen shoulder"**, **"tennis elbow"**, **fibrositis** (**fibromyalgia**) and **polymyalgia rheumatica.** Sometimes when only the ligaments, tendons and muscles are the sources of pain and limited function the term **soft-tissue rheumatism** is used.

6.2.5 **Joint hypermobility**, which is a hereditary (ie inherited) condition causing looseness and fragility of ligaments and other tissues surrounding the joints, renders the affected person more susceptible to injury. The resultant "**hypermobility syndrome**" causes problems (strains, sprains, dislocations, fractures or just pain) at various sites of injury, which may, in some cases, be persistent and lead to difficulties with mobility and self-care depending on the parts affected.

6.2.6 The diagnosis is of secondary importance - it is the disability and its consequent needs which are relevant. In all of these conditions there is a great degree of variability in relation to the need for help or effects on walking. To some extent this is dependent on the specific condition, age, severity, treatment and the response of the individual to treatment..

6.2.7 It is highly unlikely that the joints of people past middle age will be as supple, strong and resilient as those of the younger person. X rays of the joints of people past middle age (and sometimes in even younger people) may show abnormalities of the lining cartilage and the bones that make up the joints (eg thinning of the cartilage, "wear and tear", bony outgrowths, etc), but these radiological (ie X ray) findings may be present in very many people who do not have any problems in those joints. An X-ray report of joints which describes "arthritic changes" does not necessarily mean that the person with such changes has any significant pain or problem with that joint.

6.3 Osteoarthritis (Osteo-Arthrosis, Degenerative Joint Disease)

6.3.1 This disease of joints is not usually inflammatory but is characterized by wear and tear of the joints and is generally age related. It is the commonest type of arthritis. Joints which are particularly prone to develop osteoarthritis are the hip, knee, hands and spine. Past or continuing trauma (ie injury) to the joints can accelerate the onset of osteoarthritis

6.3.2 In the great majority of persons with osteoarthritis the disease is mild (with minimal or no needs) and principally affects one particular joint, which is the main source of pain and discomfort, such as the knee or hip, with minor or no involvement of other joints. The condition may have come to light

during x-ray examination, even before the symptoms were noticed. [See para 6.2.7 above]. In other people, however, the disease is more severe, causing deformity and extreme pain in affected joints. The problems may be alleviated by surgery, to replace the diseased joint with an artificial one (prosthesis). Those most commonly replaced in this way are the hip and knee joints. This operation is most often successful in significantly relieving joint pain and restoring pain-free movement.

6.3.3 In older people multiple joints are affected and, because of disuse of the joints due to pain, there may be muscle wasting. This can be a factor contributing to falls in the elderly [see Chapter 4].

6.3.4 Care Needs

(i) In osteoarthritis, the need for help and its frequency, will depend very much on the number and location of joints involved and the degree of deformity, which may be so severe that surgical intervention is necessary to correct it and to relieve pain.

(ii) Loss or limitation of hand and arm function may lead to a need for help during the day. In the early stages of the condition manual dexterity may be impaired leading to difficulty in handling common utensils. It may also make simple household tasks difficult or dangerous depending upon the degree of loss of function and reduced manual dexterity, and, of course, whether one or both hands/arms are involved.

(iii) When hip and/or knee function is limited or restricted with reduction in the ranges of movement at these joints, there may be problems with bathing, dressing and undressing the lower half of the body, going up and down stairs and rising from a chair and in walking. In the older person, help may be needed getting out of bed in the morning and back in at night.

(iv) Even when suitable, readily available, equipment or technical aids resolve some difficulties, others may persist and will depend upon individual circumstances.

6.3.5 Mobility Considerations

(i) Loss of hip and/or knee functions, especially when these are associated with problems in the ankles and feet, may lead to substantial difficulties in walking and being able to get around both in the home and outdoors. When the knee is affected the joint may become unstable, increasing the risk of falls, particularly in elderly people.

(ii) In people with long-standing and advanced osteoarthritis of weight-bearing joints (such as the hip, knee, ankles and feet, etc) treatment with pain-relieving drugs (analgesics) or anti-inflammatory medications and physiotherapy, etc, may not significantly improve walking. Where joints have been replaced, however, walking itself and pain associated with walking is usually very much improved.

6.3.6 Duration of Needs

In people with the much more common milder forms of osteoarthritis care needs are minimal and walking is not usually limited to a significant extent. However, even in people with the milder forms of osteoarthritis affecting the weight-bearing joints there may be short periods lasting several weeks when there is increased pain and stiffness which may affect care needs and walking. The duration of established care needs and walking difficulties may be reduced, or even eliminated, by successful replacement with prosthetic joints.

6.4 Inflammatory Joint Diseases

6.4.1 **Rheumatoid arthritis** is a chronic inflammatory disease involving many joints simultaneously **(polyarthritis)**, and most commonly involving the small joints of the hands and feet, in a symmetrical fashion (ie: both wrists, both ankles). The affected joints become painful, swollen, stiff and in some cases deformed. The effects of disability are generally more severe than in osteoarthritis. Its onset is most often in a younger age group than those affected by osteoarthritis - even in childhood - but it may start in the older person. Many complications (in adults and children) may be found in severe arthritis which involve various parts of the body, including the heart, small blood vessels, the lungs, kidneys, eyes and spleen.

6.4.2 **In juvenile chronic arthritis (Still's disease)**, the disease tends to affect the larger joints and growth can be impaired. Prognosis (outcome) is more favourable than in rheumatoid arthritis. For the majority of children the disease will "burn out" by the age of 16 or 18. Response to surgery such as hip or knee replacement is usually successful.

6.4.3 Other diseases which manifest principally as a chronic polyarthritis are **psoriatic arthritis, reactive arthritis** (Reiter's Syndrome), and **ankylosing spondylitis.**

6.4.4 **Psoriatic arthritis** is similar to rheumatoid arthritis, the main difference being that it is usually associated with the skin condition psoriasis, and usually leads to less overall joint disablement. Rarely it can give rise to a particularly severe form of arthritis with severe joint destruction and resulting gross disablement when care needs will be at least as great as those described for severe rheumatoid arthritis.

6.4.5 **Reactive arthritis** is a polyarthritis found in association with certain infections in other parts of the body. These are often in the gut or the urogenital system.

6.4.6 **Ankylosing spondylitis** mainly involves the joints of the spine, is commoner in men, and often leads to a stiff and rigid spine. Symptoms may become worse with time, spreading from the low back to mid back and then the neck. Unless other joints than the spine are involved care needs

and mobility considerations will be similar to those in people with the painful back [See Chapter 7]

6.4.7 Care Needs

(i) In **rheumatoid arthritis** there is characteristically a prolonged period of joint stiffness in the morning on arising from bed, and after sitting in a chair for some time. During these periods of joint stiffness the affected person has to "limber-up" slowly and so may need help with dressing, rising from bed/chair, and washing. Bathing or showering in the morning may assist in the "limbering-up" process, and help would be required for this. The duration of morning stiffness often exceeds an hour in those with active inflammation of several joints. Even in remission, between the flare-ups, damaged joints may be painful and stiff in the mornings causing difficulties in taking medication, bathing and dressing.

(ii) Damage to the joint structure may result in weakness of ligaments, tendons and surrounding muscles, causing the hands and wrists to be weak with markedly impaired grip and loss of dexterity. Involvement of the finger joints may also seriously impair grip and manual dexterity, preventing the person from handling utensils, and making it difficult to cut food. In the early stages there may only be slight impairment of manual dexterity but help may be needed in the preparation of meals. If the shoulders and neck are affected this, too, may lead to difficulties with washing, dressing, cutting up food, and eating. Putting on and taking off outdoor clothing, splints (when used) and collars may also pose problems.

(iii) Except in those with highly active disease, there should be little need for attention at night for such activities as toileting and turning in bed. During flare-ups, however, when splints and collars are used at night, removal of these to attend to toilet needs may be difficult. Help may also be required, in these circumstances, for taking pain relief medication.

(iv) Due to disuse atrophy (ie wasting of muscles) because of painful lower limb joints, falls can be a problem, generally in the older person.

(v) In **ankylosing spondylitis**, because of back stiffness, assistance may be needed with lower garments when dressing and in getting in and out of the bath.

6.4.8 Mobility Considerations

(i) Walking may well be impaired in those with active inflammation of joints in lower limbs. When the feet are affected, this may cause severe pain on walking. If knees and hips are involved, standing and sitting can be difficult and painful, and walking more severely limited.

6.4.9 Duration of Needs

(i) The needs of persons with highly active joint inflammation may lessen dramatically when spontaneous remissions occur or in response to drugs. These drug treatments are associated with an improvement in the extent and severity of arthritis. When this occurs it will be likely to do so within about one year's treatment. Patients are most responsive to treatment in the initial stages of rheumatoid arthritis (ie. 2 to 5 years following onset).

(ii) There will be older patients with a longstanding history of rheumatoid arthritis in whom the disease may be "burnt-out", leaving many of the smaller joints of the hands deformed with poor hand function or resulting in fixed deformities of lower limb joints with impairment of walking ability. In these people the needs will depend upon the overall disablement in the individual case but are unlikely to change throughout the remainder of the person's life.

(iii) In the majority of people with rheumatoid arthritis, the disease smoulders on, involving further joints, and slowly increasing levels of disability and associated needs.

6.5 Osteoporosis

6.5.1 Osteoporosis is the name given to a reduction or thinning in the total mass of bone present in the body. The precise mechanism causing this disease is unclear. It is found most frequently in women after the menopause, particularly in the older woman; and in people receiving long-term treatment with steroid compounds, eg, for rheumatoid arthritis. Sometimes the condition is noted in younger women who have had their ovaries removed (oophorectomy). Inadequate physical activity promotes generalised osteoporosis and the condition also occurs in various glandular disorders and in cases of severe malnutrition and chronic renal (kidney) disease.

6.5.2 The condition is of variable severity. In its mild form it may give rise to no symptoms and may be a chance X-ray finding. When the condition is more severe, pain may be a feature. This is usually due to fractures of the "brittle" bones, often occurring after only minor injury. Persistent backache may occur later on in the disease, due to progressive compression or collapse of several vertebrae. The healing of fractures is not usually impaired and, with healing, the pain usually subsides. There is also a tendency for the condition to improve spontaneously, or with treatment. Suitable physical exercise is also helpful.

6.5.3 Care Needs and Mobility Considerations

(i) In all but its most severe forms osteoporosis of itself may be symptomless and give rise to no mobility problems or care needs. Even when there has been very considerable loss of bone mass it will be the pain and functional limitations associated with fractures or bone collapse (particularly in the back) that may give rise to care needs and mobility problems. In these severe cases (generally in elderly women) there may well be considerable care needs arising from disability associated with fractures. These commonly occur in the region of the wrist, back and hip joint. When fractures occur in the back or in the weight-bearing joints there may well be adverse effects on walking. Progressive collapse of the spinal vertebrae may result in a shortened, curved back causing chronic pain and walking problems.

(ii) A person affected with this level of disease and its complications may also have difficulty with getting in and out of bed, rising from a chair, dressing and undressing, preparing a main meal and attending to toilet needs. Under such circumstances, and particularly in elderly people, there may be care needs both by day and by night.

(iii) When assessing the care needs which may arise, consideration should also be given to any other recorded disability(ies) which may give rise to mobility problems or care needs in their own right and which may interact with any needs arising from osteoporosis.

(iv) Although the intellect is not affected in this disease, any tendency to fall may give rise to supervisory needs in elderly frail people, because of the increased risk of broken bones, and difficulty in rising after a fall..

6.5.4 Duration of Needs

Fractures heal at the normal rate, so that any resultant disability may not last more than a few weeks or months. This is particularly so in the younger person. In elderly people with osteoporosis who have sustained frequent fractures with progressive collapse of the spinal vertebrae, significant improvement in disability and care needs is unlikely during the remainder of the person's life.

6.6 Hypermobility Syndrome

6.6.1 The hypermobility syndrome (HMS) is one of a group of inherited diseases which affect the connective tissues of the body. It is a multi-system disorder which may result in a wide variety of clinical features and disabilities.

6.6.2 Fibrous proteins (collagens, elastins, fibrillins) give the body its strength. A defect in genetic information which determines the biochemical structure and strength of those proteins may cause structural weakness in muscle, tendon, ligament cartilage, bone, the blood vessels, eyes and skin. The clinical effects depend on the function of the particular tissue affected.

Joints may become lax, unstable and hypermobile with increased tendency to dislocation and vulnerability to the effects of injury. **Bones** may become osteoporotic, predisposing to fractures. The body-shape may take on characteristic body proportions (called "Marfanoid") with long slender limbs, twisting of the spine and chest deformity. **Skin** shows increased stretchiness and the blood vessels (vasculature) may also be affected in certain of the diseases associated with HMS, such as the Ehlers-Danlos syndrome, with involvement of the heart and major vessels. **Eye** involvement may occur as dislocation of the lens in the Marfan syndrome where the lens ligament is lax and unable to hold the lens in a stable manner.

6.6.3 Approximately 10% of the adult population is hypermobile. The prevalence varies among different ethnic groups and is greater in women. The majority of affected people have no significant disability. People in some occupations or pursuits find it an asset, for example ballet dancers, gymnasts, yoga, violin players, flautists, snooker players. However, any hypermobile joint is vulnerable. The hypermobile back if used excessively, may be subject to prolapsed discs, stress fractures, spinal narrowing and other mechanical problems. People with severe forms of hypermobility syndromes (particularly those with greater degrees of tissue laxity and fragility) may lead a restricted life because their tissues are so fragile.

6.6.4 Symptoms tend to be similar in hypermobility syndromes irrespective of the cause. Due to the weaknesses in muscle, ligaments, tendons and cartilage, etc, there may be joint pain, dislocations of joints, and fractures. In any hypermobile joint, "over-use" injury can cause pain and loss of function. The same is true of the back. Stress fractures of bone are not uncommon.

Joint and/or muscle pain may be a prominent symptom. Hypermobility may be a serious potential source of problems in children. Many will develop osteoarthritis in time. With age, joint hypermobility declines, but other complications resulting from HMS may arise, such as secondary osteoarthritis; osteoporosis with resultant fractures; and loss of balance particularly in the older person, which may result in falls, especially if there is also impaired vision.

6.6.5 Care Needs

(i) People with severe forms of the hypermobility syndrome may be in frequent or constant pain that is worsened by movements, especially those involving physical effort such as lifting, moving around etc. Joints may dislocate during quite simple movements eg. with the hands or shoulders. When the tissues are damaged, physically demanding activities are also painful and give rise to care needs from another person. Depression may ensue - partly because of the pain, partly because of the inability to perform some normal daily tasks and to enjoy a normal life. Periods of rest throughout the day may be required especially after what a normal person might consider a modest bout of physical activity. Falls may occur so that certain activities such as bathing, using stairs, etc may need to be supervised, particularly in elderly people with this syndrome.

(ii) Main meal preparation, especially cutting up vegetables, opening jars, lifting pans and using taps may prove to be difficult in those with more advanced disease.

6.6.6 Mobility Considerations

(i) Because the connective tissues are lax and fragile they may be easily injured. The combination of joint pain (especially in the knees) and instability (back-bending, knees, etc) may make walking difficult. There may also be problems with balance.

(ii) The ability to walk may be limited in people with severe forms of the syndrome, requiring the use of walking aids (cane, crutches) or wheel-chair. The person may have a tendency to lose balance and fall, with difficulty getting up.

6.6.7 Duration of Needs

(i) Many of the clinical manifestations of hypermobility syndrome result from sudden injuries to the soft tissues which heal within weeks or months, either spontaneously or after medical, surgical or physiotherapy treatment. Once severe irreversible damage has taken place to joints the outlook is largely determined by whether that joint is amenable to joint replacement. Disability associated with chronic painful conditions (eg back pain or widespread osteoarthritis) is less likely to respond to treatment and may persist indefinitely.

6.7 Further Evidence

Because of the wide range of clinical manifestations and spectrum of disability and needs in musculoskeletal disorders it may often be necessary to obtain further evidence, in the form of a GP report or a report by an examining medical practitioner, in order to assess the nature, level and likely duration of needs. If the person is under the care of a rheumatologist, a report from that source may be particularly helpful.

7. THE PAINFUL BACK

7.1 Contents

7.2 Introduction

7.2.1 Low back pain with or without pain extending down the lower limb (sciatica) is a very common symptom. The known causes include disease of the intervertebral discs, inflammation or degeneration of the muscles and ligaments in the back (musculo-skeletal lesions), strain of ligaments or muscles and osteoarthritis (spondylosis) of the vertebral bones in the lower back [See also Chapter 6]. Non-specific strain of the muscles and ligaments in the lower back is the commonest cause of back pain. Terms like "lumbago", "fibrositis", or "rheumatism" are frequently used, but lack clear definition.

7.3 Acute Back Pain

7.3.1 An intervertebral disc (a flexible "shock-absorber" which separates the bones making up the spine) may burst causing pressure on adjacent nerves giving rise to acute back pain which may spread down the leg as far as the foot. The commonly used term "slipped disc" is a misnomer (ie: the disc does not slip but prolapses with pressure exerted on the ligaments of the spine or on adjacent nerves). In such circumstances the pain is often severe, rendering the person temporarily immobile. With appropriate measures the acute (sudden) pain and associated limitations in mobility normally settles within a week or two.

7.3.2 The majority of persons with acute back pain make a spontaneous recovery with no significant ensuing problems. A less fortunate minority continue to experience pain and disability. These persons usually require treatment in hospital. This may include physiotherapy, injections in the back or surgery. Persons affected in this way may go on to have persistent back pain which is usually made worse by strains due to lifting or bending.

7.3.3 Acute back pain may recur, rendering the affected person temporarily immobile each time; but each attack of pain is unlikely to last longer than a

few days or weeks at a time.

7.4 Chronic Back Pain

7.4.1 When the low back pain with or without pain extending elsewhere (ie to the lower limbs) is due to disc prolapse or longstanding degenerative or inflammatory disease of the lumbar vertebrae there may be a persistent limitation of spinal movement. The person may not be able to bend the lower spine through the normal ranges of movement, ie. there may be difficulty in bending forward or sideways or in rotating the lower spine.

7.4.2 In addition, if a nerve root is pressed upon there may be an area of tingling, numbness or, rarely lower limb weakness such as foot-drop. Pain is made worse by movement, coughing and straining. Rarely the spinal cord may become compressed by the prolapsed disc or by bony outgrowths of the vertebrae, leading to paralysis and/or impairment of sensation in the lower limbs and an inability to control bladder and bowels [See Chapter 5].

7.5 Care Needs

7.5.1 Acute back pain or recurrent episodes of back pain may be so severe that the person is unable to do anything except lie still in bed because any movement of the spine makes the pain much worse. Fortunately such severely disabling back pain lasts only a few days in the great majority of cases.

7.5.2 As a general rule the needs of persons with chronic (longstanding and persistent) back pain are usually minimal and there are periods when the back pain is minimal and of a low grade. Such pain is rarely avoided by receiving assistance, indeed it may well be inadvertently exacerbated by inappropriate assistance.

7.5.3 A person with low back pain may well have difficulty in bending but this can usually be overcome by flexing the hips and knees. Inability to bend would not usually prevent a person from dressing (except perhaps for shoes and socks - for which technical aids may be available) or from attending to toilet needs.

7.5.4 In acute episodes of back pain or in those with persistent back pain movement may increase the pain. Turning in bed, getting in and out of bed, rising from a chair, walking and turning will need to be performed carefully by the affected person to minimise this pain, but assistance from

another person is rarely required except in the acute episodes or when a persistent back pain has been temporarily aggravated. Indeed, in the absence of any muscle paralysis, the movements can normally be performed unaided and are best done so if inadvertent exacerbation or unnecessary dependence on others is to be avoided.

7.6 Mobility Considerations

7.6.1 Pain in the lower back or down one or both legs may occur on walking. However, this can usually be controlled by pain-killers (analgesics). A surgical corset may also be helpful in reducing the occurrence and/or level of pain. Apart from acute or recurrent acute episodes of severe back pain which usually do not last for more than a few weeks, it is unlikely that someone with chronic back pain, in the absence of any paralysis, would have any substantial difficulty in walking

7.6.2 In the rare cases when a nerve root is involved leading to weakness such as foot-drop, this can be controlled by a calliper and need not interfere with movement, or impair walking ability.

7.7 Duration of Needs

7.7.1 Acute or recurrent episodes of back pain are most commonly of short duration, measured in days or weeks rather than months. Care needs would be confined to these periods. Recovery, either spontaneous or as a result of successful surgical treatment (laminectomy or discectomy) usually results in complete relief of symptoms and associated disability.

7.7.2 A person with chronic back pain may experience periods of worsening superimposed on persistent low-grade pain. However, in the absence of complications, care and mobility needs are likely to be minimal. There is however a minority of people with chronic back pain in whom psychological factors such as depression or somatisation, tend to perpetuate symptoms and disability. [See also Chapter 19].

7.8 Further Evidence

7.8.1 Further evidence is most appropriate in cases where the nature and intensity of back pain (with or without pain in the lower limbs) is reported to severely inhibit walking ability or to give rise to substantial care needs by night or day. Either a factual report from the hospital or GP or a comprehensive report and examination by an examining medical practitioner (EMP) can be most helpful.

8. THE PAINFUL NECK

8.1 Contents

8.2 Introduction

8.2.1 Injury to the bones and soft tissue of the neck or "degenerative" disease of the bones and joints (spondylosis) are the frequent causes of neck pain. Pain in the neck can be acute (sudden) or chronic (longstanding). Common examples of the former are acute cervical disc prolapse and whiplash injury; the most common cause of chronic pain and stiffness in the neck is cervical spondylosis. This condition is due to degenerative changes in the neck vertebrae and the discs in between the vertebrae.

8.3 Painful Neck

8.3.1 The symptoms and any limitation of neck movements due to an acute disc prolapse or strain injury generally last for no more than a few weeks. The pain is in the region of the neck, shoulder blades and may be felt in the shoulders and the arms. The pain may be accompanied by numbness and tingling or muscle weakness resulting in a poor grip and varying degree of muscle weakness of the upper limb muscles. Neck movements may also be stiff and limited. Very rarely a disc may press on the spinal cord leading to weakness and loss of sensation in upper and lower limbs, along with difficulty controlling the bladder and bowel.

8.3.2 Cervical spondylosis is part of the ageing process. It is a form of osteoarthrosis. On X-ray there may be well developed bony and disc changes in cervical spondylosis which cause no significant pain or disability. Most people over the age of 50 years will show some changes due to cervical spondylosis on X-ray of the neck. The condition comes on gradually, in some cases it may be made worse by trauma. The symptoms are similar to those in acute lesions but are usually less severe. In some cases due to progressive compression of the nerve roots there may be muscle wasting and weakness of the upper limbs.

8.4 Care Needs

8.4.1 The help that is needed generally relates to tasks that involve the use of upper

limbs ie dressing, washing hair, impairment of grip in using household utensils. The symptoms from cervical spondylosis can often subside spontaneously, or in response to treatment like a collar, analgesics or physiotherapy. In all but acute episodes of pain and stiffness due to a prolapsed disc or following severe neck strain, which rarely last longer than a few months, the pain and disability due to cervical spondylosis rarely gives rise to significant care needs. When there is evidence of muscle wasting or significant loss of sensation in the upper limbs and hands care needs as described above may be present.

8.5 Mobility Considerations

8.5.1 There may be difficulty in walking in cases of acute cervical disc prolapse when pressure on the spinal cord has produced leg muscle weakness. In people with cervical spondylosis it is unlikely that there will be any significant effects on the ability to walk unless there is evidence of irreversible damage to the spinal cord [see also Chapter 18]. In all such cases there will be a history of hospital admission, and in the acute cases, frequently of surgical intervention. In elderly people with advanced cervical spondylosis there may be pressure on the vertebro-basilar arteries providing blood to the brain. Certain movements of the neck can result in brief episodes of dizziness and/or unsteadiness. Rarely such episodes of vertebro-basilar insufficiency can result in brief altered consciousness or loss of consciousness.

8.6 Duration of Needs

8.6.1 In cases of acute disc prolapse the condition is likely to settle within a few weeks to months with treatment (including surgery). In cervical spondylosis, the established needs tend to be long-standing though they may be intermittent.

8.7 Further Evidence

8.7.1 Further evidence is most appropriate in these cases: a factual report from the hospital or GP or an examination by an examining medical practitioner should be helpful..

9. AMPUTATION OF LIMBS

9.1 Contents

9.2 Introduction

9.2.1 Removal of limbs or parts of limbs may be necessary at any age as a result of various conditions, mostly peripheral vascular disease, but causes may include malignant disease, injury (trauma), or congenital deformity. A common reason for amputation in adults, particularly in elderly people, is gangrene of part of the lower limb as a complication of peripheral vascular disease - often associated with diabetes mellitus [see Chapters 13 and 17]. 60% of all amputees are over 60 years old. Congenital absence of limbs or parts of limbs may have much the same effect as amputation.

9.2.2 An artificial limb, or part of a limb, is known as a prosthesis. It is important to realise that such a prosthesis may be functional ie. able to reproduce much of the function of the lost limb, or may be mainly cosmetic. Many upper limbs protheses are purely cosmetic, though some have a relatively good degree of functional capability. Where a large part of an arm is lost, both functional and cosmetic prostheses may be used at different times, and training in their fitting and use is required. In general, lower limb prostheses are all functional, but their effective use depends on the level of amputation, the person's age, build, motivation and state of health.

9.2.3 Modern developments, using the latest technology, aim to produce a more functional prosthesis, using remaining nerves and muscle groups in the residual limb for their control, though this is, as yet, only widely used when there has been loss of part of the upper limbs.

9.3 Upper Limb Amputations

9.3.1 Levels vary from loss of the tip of a finger to the removal (or absence) of a whole limb or limbs, including the whole shoulder (forequarter amputation).

9.4 Care Needs

9.4.1 Care needs will depend very much on the remaining natural function of the limb and the type of prosthesis fitted. Loss of significant parts of both upper limbs is likely to be very disabling and to result in care needs.

9.4.2 Care needs may also depend on the dominance of the affected limb. Loss involving the dominant limb (ie. the right arm in a right-handed person) is likely to be more disabling than loss to the same extent of the other, non dominant limb.

9.4.3 Loss of a thumb is more disabling than loss of a finger, because many day-to-day tasks depend on an adequate grasp between finger and thumb. Loss of a thumb or of a single finger is however unlikely to result in care needs unless there are added complications such as arthritic changes involving the hands.

9.4.4 In some cases the use of simple aids can help the person manipulate common household utensils.

9.4.5 Care needs may be associated with fitting a prosthesis, and in the case of a functional prothesis a period of training in its use is likely to be needed.

9.5 Mobility Considerations

9.5.1 Mobility will rarely be affected, but there may be balance problems, particularly if large parts of both upper limbs are absent.

9.6 Lower Limb Amputations

9.6.1 Levels can vary from the loss of the tip of a toe to amputation through the hip joint, or even including the removal of part of the pelvis (hemipelvectomy).

9.6.2 Occasionally, complications may arise, such as swelling (oedema) of the stump, infection, friction which may lead to blisters and sore areas, or skin problems which rarely may be related to materials within the prosthesis. Bony spurs or regrowth of bone or neuromas (painful nerve swellings) may develop at the stump leading to a need for it to be refashioned. Following any of these complications, it may be necessary to leave the limb off, as continued use could lead to worsening of the condition. The person would be required to return to the Disablement Service Centre for treatment that may include renewal of the socket, either as a temporary or more permanent measure.

9.6.3 It is normal for the person to feel that the lost limb is still there (phantom sensation) and occasionally this may be painful (phantom pain). Pain in the

residual limb may arise as a result of painful swelling at the end of cut nerves (neuroma). In addition to problems with the residual limb there may be problems in other areas such as the back or the remaining limb. In particular, peripheral vascular disease severe enough to lead to amputation is likely to affect the remaining limb also. The onset of arthritis may be accelerated due to extra dependence on the remaining limb.

9.6.4 Sometimes, long term (10 - 15 years after amputation) sequelae may arise due to twisting of the spine (scoliosis) causing chronic back pain, balance problems, chronic irritation of the stump and the earlier onset of arthritis in the weight-bearing limb.

9.7 Care Needs

9.7.1 Care needs may be associated with help in fitting the prosthesis, care for the stump, and dealing with complications. Except in very young and very elderly people, such needs are likely to be minimal. Usually, the higher the level of amputation the greater the needs.

9.7.2 Until the person adapts to the prosthesis help may be needed to get in and out of bed, out of a bath and going upstairs and downstairs. The length of time over which help will be needed will vary from person to person with age and general health. Adaptation is more difficult in elderly people and they may also have the problem of arthritis in the other joints. If the person has had both legs amputated, then their care needs may be greatly increased.

9.8 Mobility Considerations

9.8.1 Following the majority of amputations in otherwise fit persons, a prosthesis is fitted once the wound has healed, and the person is trained to walk, using aids such as a stick or walking frame as necessary.

9.8.2 The functional level achieved will depend on a number of factors: the age, physical and mental fitness of the person; their motivation; the level of amputation and construction of the stump; and the availability of rehabilitation programmes. A young person, otherwise fit, will usually regain useful mobility following a period of rehabilitation of anything from one month to a year. Rehabilitation will be delayed by the presence of complications or obesity.

9.8.3 Some people, particularly elderly persons and those with bilateral above-knee (A/K) amputations, never learn to become independently mobile, and remain wheelchair users.

9.8.4 The level of amputation will affect functional achievement. In hemipelvectomy or amputation through the hip joint, although prostheses are satisfactory, they tend to be heavy. Walking is likely to be extremely fatiguing, and the quality of walking will be less than that of a person whose

amputation is at a lower level. With above - knee amputations, provided the stump is of adequate length. it is possible in most cases to fit a prosthesis, and a person with an amputation below knee (B/K) level can normally be fitted with a prosthesis. Amputation of the forefoot or toes may require no more than the fitting of special footwear.

9.8.5 Balance problems may occur with amputation at any level, even the toes, especially the great toes. Such problems however are normally short term. Balance problems may be increased if the remaining limb is damaged or diseased.

9.9 Duration of Needs

9.9.1 Needs will vary with many factors, including age, general health, reason for amputation, level of amputation and the presence of other disabilities. Following amputation, there is often a "grief" reaction to the loss of the limb and, if this is particularly severe in an individual, the rehabilitation process may be prolonged and counselling will be required.

9.9.2 In cases of particular difficulty, advice from a Medical Services doctor may prove useful.

9.10 Further Evidence

9.10.1 The most appropriate sources would be the GP, physiotherapist or Disablement Services Centre.

10. VISUAL AND HEARING IMPAIRMENT

10.1 Contents

Related conditions considered in other chapters:-

10.2 Visual Impairment

10.2.1 Visual impairment occurs in a range of conditions in which complete loss of vision is uncommon. Most people who are registered blind have some degree of residual vision. In order to be registered blind a person must be unable to do work for which vision is essential. However, in deciding on the level of care and mobility needs this is not particularly helpful. It is probably more useful for these purposes to regard someone as blind if their vision is so impaired that they are unable to get around in unfamiliar places without the assistance of another person.

10.3 Care Needs

10.3.1 Vision is used in the completion of almost all daily activities. Thus when a person becomes blind suddenly, there are likely to be extensive care and mobility needs. Loss of vision in this way will require a period of training, adaptation and the learning of new skills. During this period the person is likely to require help from another person several times a day with a range of activities. Even with sudden loss of vision, there would not necessarily be any night needs. If for example, a person needs to use the toilet, it should be possible either to get to the toilet unaided, or to use a bottle or bedside commode.

10.3.2 This period of training and adjustment usually lasts for about two years. However, the time taken by an individual person may vary. If a person over the age of 65 has not adapted, then it is likely that the daytime care needs will persist indefinitely. In younger persons a more prolonged period of adjustment and training may be necessary before independence is achieved. This additional training may last between two and five years depending on the individual.

10.3.3 There will be a number of factors which determine whether a person

achieves the expected level of independence. These include the precise nature of the eye condition, age, motivation and the presence of other disabilities. It should be noted that some people with sudden loss of vision may not receive the necessary training to enable them to adapt. Even with adaptation and training, many people may continue to require help with household tasks.

10.3.4 When the onset of visual impairment has been gradual rather than sudden, most people make progressive adjustments over a period of time. Consequently the care needs are unlikely to exceed those of a person who has had a sudden loss of vision and been able to make the necessary adaptations to this. However, it should also be recognised that the majority of such people lose their sight when they are older. In some of these this progressive adjustment actually means a progressive restriction of activities which they are no longer confident or capable of undertaking on their own. A consideration has to be made on whether it is reasonable to expect them to neglect such activities, or whether they should really have assistance from another person.

10.3.5 Sudden changes of circumstances, eg a change of home with unfamiliar surroundings, may have an effect on the independence of a visually impaired person; in effect the person may have to start the adaptation process all over again.

10.4 Mobility Considerations

10.4.1 The majority of severely visually impaired people are likely to need guidance and supervision to find their way around in unfamiliar surroundings, regardless of whether the onset of the impairment has been sudden or gradual.

10.5 Hearing Impairment

10.5.1 A person should be regarded as having no useful hearing when residual hearing even with artificial aids is, in practice, insufficient for spoken language, so that some other form of communication (lip-reading, sign-language, etc) has to be used.

10.5.2 Uncomplicated total deafness of sudden onset is rare. It occurs when there has been long-standing deafness in one ear to which a total hearing loss on the other side is added, but it may on occasion arise as a sudden event affecting both ears.

10.6 Care Needs

10.6.1 Persons with normal mental function and intellect who suffer the sudden onset of total deafness should nonetheless be able to avoid common dangers and should not expose others to danger. They will, however, need the assistance of others with communication during a period of learning lip-reading, sign language or alternative means of communicating with other people. The period of adjustment and training may take at least one year but may vary in the individual person, and in some will not be successfully achieved. However, in elderly persons the process of learning and adjustment usually takes several years. The duration of this extended period of rehabilitation will depend upon the overall effects of other age-related disabilities which may be present in the individual elderly person.

10.6.2 Factors such as the physical health, mental state and any other co-existing disablement may impair and prolong the period of learning and rehabilitation in an individual case.

10.6.3 People with deafness of gradual onset, not complicated by other disability should be capable of carrying out their bodily functions unaided and should also be able to avoid common dangers both in and out of doors.

10.7 Combination of Blindness and Deafness

10.7.1 Care Needs

People with the degree of visual impairment defined in paragraph 10.2.1 who also have no useful hearing as defined in paragraph 10.5.1. are likely to be unable to avoid common dangers both in and out of doors. People who are both deaf and blind are unable to use one sense to compensate for loss of the other. Help with communication is also a key requirement. Unless there are additional disabilities which would cause a person to be up during the night, attention or watching over are not usually required by reason of combined blindness and deafness.

10.7.2 Mobility Considerations

A person may satisfy the conditions for the higher rate mobility component if he is both deaf and blind, and as a result he is unable to walk to his intended destination out of doors without the assistance of another person. The degrees of disablement resulting from loss of vision and loss of hearing must amount to 100% and 80% respectively. Assessment of the mobility needs of persons with lesser degrees of disablement must take into account the compounding effects of dual sensory loss on the need for guidance and supervision in unfamiliar surroundings.

10.8 Further Evidence

10.8.1 The degree of disability resulting from blindness and deafness requires expert assessment. Advice from a Medical Services doctor on interpretation

of existing evidence, or the most appropriate source of further evidence, would be most helpful.

11. CARDIAC AND RESPIRATORY CONDITIONS

11.1 Contents

11.2 Conditions Considered

Coronary Artery Disease	11.3.3
Ischaemic Heart Disease	11.3.3
Angina	11.3.3
Valvular Disease of the Heart	11.3.6
Heart Failure	11.3.7
Chronic Obstructive Airways Disease	11.3.8
Chronic Bronchitis and Emphysema	11.3.8
Bronchial Asthma in Adults	11.11.
Bronchiectasis	11.12.
Related Conditions Considered in other Chapters:	
Cystic Fibrosis	**Chapter 44**
Asthma in Children	**Chapter 45**

11.3 Introduction

11.3.1 Diseases of the heart and lungs are important in this context for two reasons. First, they are very common. 17% of men and 8% of women between the ages of 40 and 60 have chronic bronchitis. In England and Wales 30% of deaths amongst men and 22% amongst women are due to ischaemic heart disease. They are considered together in this chapter since the resulting disabilities which give rise to care and mobility needs are very similar.

11.3.2 These diseases are also important for the degree of disability they cause. Many of the diseases are progressive and often lead to severe disability which can persist for many years.

11.3.3 Ischaemic Heart Disease (Coronary Artery Disease)

(i) Ischaemic heart disease (coronary artery disease) is caused by narrowing of the arteries that supply blood to the heart muscle. Angina (chest pain on exertion) is often the first symptom although for many the first sign of the disease is the severe pain of a myocardial infarction (heart attack). Sometimes the first sign of disease is sudden, unpredictable death.

(ii) For the majority of people with ischaemic heart disease modern treatment is effective in controlling the frequency and severity of attacks of angina. Most should be able to lead a normal or near normal life, although the pace of life may have to be reduced. Even after a heart attack most people are back to normal exercise levels within two or three months.

(iii) In a small number of cases treatment fails to limit chest pain, even at rest, or complications developing, such as heart failure. Some of these people can be helped by surgery to the arteries of the heart (coronary by-pass surgery) or by stretching the narrowed arteries with a special balloon device or, in extreme cases, by heart transplantation, but many will become increasingly disabled as time goes on.

11.3.4 Valvular Disease (Rheumatic Heart Disease)

Conditions that damage the valves of the heart may also result in an impaired pumping action of the heart. In the past, valve damage usually followed rheumatic fever but nowadays is more often due to degeneration or wear and tear to the valve tissues. The effect of valvular damage is to put additional strain on the heart. Treatment, either by drugs or by valve replacement surgery, is intended to minimise this strain. In some instances, however, this does not work and heart failure develops.

11.3.5 Heart Failure

Heart failure is the term used to describe the situation when the heart is no longer able to maintain an adequate output of blood. This causes swelling of the feet and ankles because of fluid retention and breathlessness from accumulation of fluid in the lungs. In its early stages drugs can be used to control symptoms, but if the cause of the heart failure is irreversible then the severity of the heart failure will gradually increase, adding greatly to the disability already present.

11.3.6 Chest Disease

(i) Chronic obstructive airways disease is a term used to describe a condition in which there is irreversible and usually progressive limitation of airflow into and out of the lungs. Both chronic bronchitis and emphysema come within this definition. They are caused by cigarette smoking.

(ii) In these conditions there is progressive destruction of the lung tissue, causing cough, excessive production of sputum and increasing

breathlessness. The situation is made worse by repeated chest infections which add to the destruction of the lung tissue. Various drugs are used to relieve the symptoms of these diseases but in many cases a stage is reached where the person has severe impairment of respiration, breathlessness at rest, or is even bed-bound. Complications such as heart failure [11.3.7] add to the already severe disability.

11.4 Disability in Diseases of Heart and Lungs

11.4.1 Chronic (long-standing) conditions affecting either the heart or the lungs often result in similar disability. In most cases of heart disease, and in the early stages of chest disease, medical treatment is effective in controlling symptoms and the affected individual has little or no disability. In some cases of heart disease however, and in the later stages of chest disease, the disease progresses so that treatment becomes less effective. In these circumstances the disability can be very severe.

11.4.2 The main symptoms arising from all these conditions are breathlessness, swelling of the feet and ankles because of fluid retention and chest pain. It is the combination of these symptoms that leads to the disability. Symptoms usually occur on exertion, but in advanced cases can occur at rest. In advanced cases reduced oxygen supply to the brain may lead to confusion and disturbances of consciousness.

11.5 Care Needs

11.5.1 The first problem likely to be noticed will be the development of chest pain or breathlessness when the person exerts himself more than usual. This will progress to pain or breathlessness even on normal exertion. At this stage the person should have little or no problem in attending to bodily functions, although climbing stairs may be difficult.

11.5.2 As symptoms increase in frequency and severity, the person may also begin to experience problems with breathlessness in bed. He may find that breathing is alright when he is propped up but, as during sleep he slides down in the bed he becomes increasingly breathless. This may be so bad that he is not able to pull himself back upright and he needs help from someone else in order to prop him up so that he can breathe more freely. By the time a person has developed such problems at night there will almost always be significant problems during the day.

11.5.3 Further progression of the disease means that even slight exertion such as that involved in dressing, washing and preparing a meal will cause severe breathlessness or pain. In the circumstances it would be reasonable for the

person to have help with these activities. Eventually, the stage is reached when even the slightest exertion causes severe symptoms and the affected person is effectively chair or bed-bound. At this point he will be in need of a great deal of help both by day and at night.

11.6 Mobility Considerations

11.6.1 The development of chest pain or breathlessness when the person exerts himself more than usual should not at first limit walking distance to any significant extent. The person should still be able to walk a reasonable distance albeit more slowly than before.

11.6.2 As symptoms increase in frequency and severity, the person's exercise tolerance is reduced to the stage where walking is limited either by extreme breathlessness or by chest pain that is not relieved quickly by drugs. When a person has chest pain of such severity that it restricts mobility in this way, they will almost always have been referred for consideration for cardiac surgery.

11.6.3 In those people whose breathlessness is due to the more severe, later stages of progressive chronic bronchitis, there may also be heart failure. Cough which produces sputum (phlegm) is also a most debilitating feature. In these people with severe chronic bronchitis breathlessness may be present on the slightest exertion and walking will be very limited.

11.7. Duration of Needs

11.7.1 Once help is required, the need for it is likely to be lifelong. A successful bypass operation or heart transplant can, however, change the situation dramatically for some people where the disability is due to heart disease. Transplantation of the lungs is much less commonly encountered except in the younger person whose lung disease is due to the effects of Cystic Fibrosis [See Chapter 44].

11.8 Further Evidence

11.8.1 A factual report from the GP may help to clarify the needs of someone suffering from heart or chest disease. Further information on any residual needs in those persons who have undergone a successful heart transplant or coronary by-pass may best be obtained by a factual report from the relevant hospital where the person is being followed up as an outpatient. Lung function tests will have been carried out on people with disabling chronic bronchitis. The results of these special tests will demonstrate poor lung function in those who have significant care needs and substantial limitation of walking. Advice may be needed from a Medical Services doctor to ask questions of the GP or hospital about the lung function tests and how these should be interpreted in assessing the degree of ensuing disability.

11.9 Oxygen Therapy

11.9.1 There are occasions when the use of oxygen in the home is valuable. Oxygen in portable form as a small light cylinder which the disabled person can carry and replenish as required from a main cylinder kept at home may be prescribed. Used in this way, the person can take a few breaths of oxygen before undertaking exertion which would otherwise cause breathlessness, such as mounting stairs or moving from one building to another. Portable oxygen should have the effect of reducing the amount of assistance required as the person can manage the apparatus unaided.

11.9.2 In some cases where the disease has progressed to the stage of severe disability, oxygen may be prescribed for continuous use over a prolonged period up to 15 hours per day. This has the effect of promoting a sense of wellbeing and of prolonging survival. Oxygen for prolonged use may be supplied from large cylinders or by means of an oxygen concentrator, a machine which concentrates oxygen in normal air to very high levels. The use of oxygen at this stage of severe disability is not likely to reduce the significant amount of assistance required.

11.10. Cardiac Pacing

11.10.1 Cardiac pacemakers are used mainly in the treatment of heart block (a fixed slow heart rate), though other forms of dysrhythmia (irregular heartbeat) may occasionally be treated by this means.

11.10.2 Two types of pacemaker are currently in use, the demand pacemaker which comes into action when the pulse rate falls below a predetermined level and the physiological pacemaker which can also speed up on exercise. Both are very reliable and people fitted with them attend hospital for regular checks to ensure there are no problems. Batteries are changed as necessary. A person fitted with a pacemaker is very unlikely to have any care or mobility needs of significance on that account alone.

11.10.3 If it is suggested that a person fitted with a pacemaker, has care or mobility needs, a report from the GP or an examining medical practitioner may be helpful.

11.11 Bronchial Asthma in Adults

Bronchial Asthma in Children is described separately in Chapter 45

11.11.1 General Description

(i) Asthma is due to reversible narrowing of the air passages in the lungs

brought about by an over-reaction to various stimuli, such as air pollutants, allergens, cold air, emotional stress, etc, which causes cough and/or wheezing. Modern medical treatment for asthma is very effective and most sufferers have few or no symptoms for many months of the year. Treatment is usually given by inhalers which can be divided into those which act immediately and those which prevent attacks if given regularly. Inhalers are usually self-administered. In more severe cases the same drugs can be nebulised into water droplets using a small machine. The use of a nebulizer in adults rarely requires the assistance of another person unless other complicating conditions are present (eg. arthritis of the hands, mental impairment, etc) Most people with asthma can live a normal active life.

11.11.2 Care Needs

(i) Even for those who suffer from regular attacks additional treatment (usually with steroid tablets or inhalations) will quickly be effective and these treatments can usually be taken without assistance. Even when some other condition such as loss of manual dexterity or mental impairment makes assistance with treatment necessary, it is unlikely attacks will persist with any frequency over a prolonged period.

(ii) For many people, the onset of an asthmatic attack can be a frightening experience, even if the attack is not severe. Some of these people will feel the need for another person to be present at all times, more for reassurance than anything else. However, the affected individual is usually capable of treating the attacks without help, is seldom in any serious danger and could summon help should it be required.

11.11.3 Further Evidence

(i) If care in excess of that described above is claimed to be needed, a report from the GP or an examining medical practitioner may be helpful in clarifying the actual needs. The frequency of hospital admissions, if any, may also be a useful indication of the severity of the disorder.

(ii) A report on peak expiratory flow readings may be useful as a measure of severity. It is an indirect measure of the degree of obstruction of the air passages. After taking a deep breath, the person blows hard into a peak flow meter, and the reading (expressed as litres per minute) is compared with that expected of a healthy person of the same age. Some persons with asthma will have their own mini peak flow meters. The GP or an EMP may also be able to report on peak flow readings. The result of a single reading must be considered in the context of the situation at the time, ie.

whether it was taken during an acute attack or in between attacks.

11.12 Bronchiectasis

11.12.1 General Description

This condition is characterized by enlargement of the small air passages within the lungs. Sputum (phlegm) is prone to accumulate in the dilated air passages and to become infected. The condition may be produced in different ways. In some cases it is present from birth due to a genetic abnormality, but is usually a result of severe chest infections in childhood, often arising as a complication of whooping cough, or measles. It may develop in adult life as a complication of pneumonia, tuberculosis or lung cancer and is invariably present, to some degree, in cases of cystic fibrosis. Although the disease runs a chronic course characterized by flare-ups due to recurrent chest infections, antibiotics have greatly improved the outlook.

11.12.2 Care Needs

(i) The degree of disablement is very variable depending on whether the condition is localised or widespread throughout the lungs. In many cases, disablement is slight, consisting merely of recurrent episodes of cough with infected sputum, but with no symptoms in the intervening periods and no deterioration in general health. Occasionally, when the disease is localised, it may be eradicated by removal of the affected portion of the lung.

(ii) In all cases physiotherapy in the form of postural drainage is important in order to keep the dilated air passages free from sputum and hence reduce the likelihood of infection. Most adults are taught, and are able to perform, postural drainage on themselves.

(iii) Persons with advanced disease may suffer from a chronic cough with large amounts of infected sputum being produced each day. Progressive lung damage occurs and leads to a pattern of disablement and consequent care as described for other chronic lung conditions earlier in this chapter. However, to this overall disablement must be added the need for postural drainage which the individual may no longer be able to perform unaided as breathlessness and incapacity increase. Occasionally blood may be coughed up in large quantities leading to anaemia and significantly increasing the degree of breathlessness.

11.12.3 Mobility Considerations

Persons with advanced disease and progressive lung damage may reach a stage where exercise tolerance is reduced by extreme breathlessness as described earlier in this chapter.

11.12.4 Duration of Need

In persons with advanced disease other than in those suitable for surgery, significant improvement is not to be expected.

12. CEREBROVASCULAR DISEASE

12.1 Contents **Paragraph**

12.2 Conditions Considered

Stroke	12.4
Cerebrovascular Accident (CVA)	12.4
Cerebrovascular Disease	12.4

Related conditions considered in other chapters:

Paralysis	**Chapter 5**
Dementia	**Chapter 21**
Falling	**Chapter 4**

12.3 Introduction:

12.3.1 Increased life expectancy has led to a higher proportion of the population in the older age group. This in turn has increased the prevalence of cerebrovascular disease in the community. There are two main manifestations of cerebrovascular disease: stroke and dementia. Dementia is dealt with in Chapter 21. This chapter is concerned with strokes.

12.4 Stroke, Cerebrovascular Accident (CVA)

12.4.1 Clinical Description/Features:

(i) A stroke is the popular term used for a cerebrovascular accident (CVA) which is an interruption of the blood supply to, or haemorrhage into, a part of the brain resulting in impaired function of the brain and nervous system. The part of the brain deprived of a blood supply will die and the resulting impairment of body function (ie. neurological deficit; see below) will remain.

(ii) The features of a stroke depend upon the site of damage to the brain. The

most common site of brain damage results in **hemiplegia** (weakness or paralysis of part or all of one side of the body), **hemianaesthesia** (loss of sensation of part or all of one side of the body), and **hemianopia** (loss of vision to one or other side). Strokes affecting the right side of the body are commonly associated with **dysphasia** (difficulty with expressing and understanding language), and strokes affecting the left side are associated with perceptual problems (lack of awareness of the affected part of the body).

(iii) Stroke affecting a part of the brain called the brain stem may produce **vertigo** (a disturbance of balance with sensations of movement or rotation), difficulty with speech, chewing and swallowing, weakness of the face, difficulty in controlling movements of the eyes, **ataxia** (unsteadiness and incoordination of movement) and nystagmus (fine rapid movements of the eyes).

(iv) Stroke affecting the cerebellum causes, in the acute phase, incoordination, decreased muscle tone, and some loss of limb power. **Dysarthria** (difficulty with articulating speech), nystagmus, ataxia and disorders of gait, are possible long term effects.

(v) Unless the stroke is so severe as to cause death within a few days a degree of recovery from the initial level of disability can be expected. One third will eventually make full recovery, one third will remain disabled to some extent, and the remaining third will remain severely disabled and dependent. Most of the recovery takes place within the first six months; no improvement of functional significance can be expected after one year. Recovery and the effectiveness of rehabilitation depend upon many factors including the size and site of the brain damage, the presence or absence of other disabling conditions (dementia, cardiac disease, lung disease, arthritis, mental illness, depression, blindness), motivation and the age of the disabled person.

(vi) Some affected individuals are prone to series of repeated episodes which resolve within 24 hours (called transient ischaemic episodes) which may cause temporary paralysis, repeated episodes of unconsciousness or altered awareness, and difficulties with speech or other special senses.

12.5 Care Needs

12.5.1 Even when the upper limb remains without useful function the use of technical aids such as special cutlery and fastenings on clothes may enable the person to manage alone. If the stroke affects the dominant upper limb, full independence will be more difficult to achieve; however, any need for attention is likely to be restricted to short but necessary significant periods of help in relation to specific tasks such as dressing, washing, or cutting food.

12.5.2 Sensory inattention and dysphasia make communication very difficult and if these problems do develop a considerable amount of attention will be

required.

12.6 Mobility Considerations

12.6.1 A majority of younger people with stroke without other complications can be expected to achieve a considerable degree of independence. Most will learn to walk, although some will require the assistance of mechanical aids such as a walking frame, tripod or walking stick. These persons will usually be independently mobile within the house, but their capacity for walking out of doors may remain restricted in terms of distance and speed. Mobility may also be adversely affected by ataxia and gait disturbance in persons who have suffered cerebellar stroke.

12.7 Duration of Needs

12.7.1 Because rehabilitation after a stroke takes time, it may not be possible to make a decision about the long term needs for attention at the outset. In younger people whose condition has not yet stabilized, improvement may well continue for 1 year.

12.7.2 Older people, even when free from complicating conditions, are less likely to achieve independence. Clearly, there can be no sharp cut-off point; each case must be considered individually in the light of the evidence, but the older the person, the less likely will independence be achieved. In addition, older people are more likely to have other complicating conditions such as cardiac disease or dementia which may contribute to their attendance needs.

Where attention needs are present in persons aged over 70, they are likely to persist for life.

12.8 Further Evidence

12.8.1 Should there be any difficulty in assessing a particular case a factual report from an appropriate social worker, occupational therapist, physiotherapist or the GP is likely to help clarify the actual needs.

13. PERIPHERAL VASCULAR DISEASE

13.1 Contents

13.2 Introduction

13.2.1 Atherosclerosis is an age-related condition affecting arteries. Affected blood vessels become "furred up" and narrowed which makes them liable to thrombosis (blockage). This results in serious impairment of the blood supply to important structures within the body. When this affects the lower limbs the term peripheral vascular disease or peripheral arterial disease is applied.

13.2.2 The principal effect of this condition is to reduce mobility by causing calf pain on exercise. Some people also develop ulcers on their feet or ankles. These are very difficult to treat and may take many months to heal.

13.3 General

13.3.1 The condition can develop suddenly with complete blockage of a major artery. Immediate surgery is usually required to try to remove the blockage if the affected limb is to be saved. Unfortunately, in many cases this is not successful and amputation of the limb becomes necessary. [See Chapter 9]

13.3.2 More commonly the condition develops slowly. Muscle pain in the calf or some other part of the lower limb on exercise, relieved by rest (intermittent claudication), is the first symptom. This can progress through persistence of pain even at rest and/or ulceration that will not heal to frank gangrene of the lower part of the limb.

13.3.3 Various drugs have been tried in the treatment of intermittent claudication without success. If severe, surgical reconstruction of the blocked arteries is the only treatment with any chance of success. Once gangrene has developed amputation of the affected limb becomes necessary.

13.4 Care Needs

13.4.1 In the early stages of the disease there should be no significant care needs. As the disease progresses a person's mobility will be restricted but they should still be able to attend to bodily functions without help. In the absence of other disability, supervision should not be needed.

13.4.2 Even if the stage is reached when there is pain at rest the person should be

able to cope with bodily functions albeit slowly. Pain is often more severe at night but the person should still be able to take pain-killing tablets without help. Again, in the absence of other disability, supervision should not be needed.

13.4.3 If amputation becomes necessary there will be a period of increased need for help. Many people adapt to artificial limbs quickly, but others, particularly older people and those with bilateral amputations, may be confined to a wheelchair or crutches for many months [see Chapter 9].

13.5 Mobility Considerations

13.5.1 In the early stages mobility problems are minimal. As the condition progresses, the distance a person can walk before developing pain will become less and less and rests to relieve the pain will become longer and more frequent. The stage may be reached when the person can only walk a few yards before pain starts.

13.5.2 Should an amputation become necessary mobility will be severely restricted until the person can adapt to the artificial limb. For those who remain confined to a wheelchair or crutches this restriction will continue [see Chapter 9].

13.6 Duration of Needs

13.6.1 Peripheral vascular disease is progressive. Once problems with mobility have become established they will continue unless surgical reconstruction of the affected arteries is carried out. If, despite surgical treatment, there has been no change in exercise tolerance, then the problem is likely to continue.

13.6.2 If amputation has been necessary, there is the period of adaptation during which the person may well have care needs as well as mobility problems. The length of this period will depend on the age and general health of the person, the site of the amputation(s), the presence or absence of other disabilities and the person's motivation to become independent again [see Chapter 9].

13.7 Further Evidence

13.7.1 In most cases the needs should be clear. If the level of disability or duration of needs require clarification a factual report from the GP, Disablement Services Centre or hospital, if attended, should help.

14. EPILEPSY

14.1 Contents

14.2 Conditions Considered

14.3 Introduction

14.3.1 The condition of epilepsy refers to a liability to attacks in which there is sudden loss of consciousness or altered awareness which may or may not be accompanied by a convulsion. Apart from the liability to attacks, the person with uncomplicated epilepsy is not otherwise impaired physically or mentally by virtue of the epilepsy alone.

14.3.2 The vast majority of people with epilepsy successfully hold down suitable jobs, marry, bring up children and in every way lead full lives. People with epilepsy cannot generally be considered as being in substantial danger. The liability to have fits does not in itself mean that a person needs attention or supervision. Only a very small minority of people with epilepsy in whom there are either special features relating to their fits or complicating conditions will be sufficiently disabled to require attention or supervision to any significant degree.

14.4 Classification and Clinical Description

14.4.1 There are many classifications of epilepsy. A full classification would be extremely complicated, but the following is likely to be useful in determining the care and mobility needs a person is likely to have.

14.4.2 **Partial seizures**. These are seizures which begin locally or focally affecting a single part of the body or resulting in a particular type of abnormal behaviour. Various types of partial seizure may occur:-

(i) Simple partial seizures in which consciousness is not impaired and where there may be just abnormal and uncontrolled movement of one part of the body.

(ii) Complex partial seizures (formerly know as temporal lobe or psychomotor epilepsy). In these the person has impairment of consciousness or disturbed awareness. He may continue to do what he is doing without being aware of the fact or he may behave in a bizarre or inappropriate way.

(iii) Partial seizures becoming secondarily generalised. In these, partial seizures end with the person having a convulsion.

14.4.3 **Generalised seizures**. These include disorders which were previously known as grand mal or generalised tonic-clonic seizures; petit mal, and myoclonic seizures.

(i) In the major type of generalised seizure the person loses consciousness with or without warning, may go rigid or have repeated movements of arms and legs (a convulsion). He may bite his tongue and may be incontinent

(ii) Absence seizures. These are either typical (previously known as petit mal) or atypical. In both types, the person usually has a momentary loss of consciousness. The person will be unaware that this has happened, but it may be apparent to an observer who may note a blankness or brief interruption in conversation. These attacks may be very frequent.

14.5 Factors Influencing Care Needs

14.5.1 There are a number of factors which, in combination, will influence the amount of attention or supervision a person with epilepsy needs. A knowledge of as many of these facts as possible will give an overall picture of the disability caused by the attacks in the individual person and determine the care needs. No single factor can be decisive. The factors include:-

(i) The duration of the epilepsy

(ii) The nature of attacks.

(iii) Whether the person gets any warning, either of a general nature such as restlessness or irritability for some time prior to the attack, or of a more specific nature in the form of an aura (a subjective sensation which

precedes, and may give warning of, an impending epileptic fit), as this will influence the opportunity to protect himself against injury. If there is an aura, its duration will affect the person's ability to put himself out of danger from the impending fit. The aura takes various forms and may include an unusual smell, or taste, or a tingling sensation in some part of the body.

(iv) The duration of the loss of consciousness or altered awareness.

(v) Whether there is a convulsion.

(vi) Whether the fit is accompanied by incontinence.

(vii) Whether the attack is followed by confusion or automatic behaviour. This type of behaviour varies widely and may be very specific to the individual. It may range from bizarre but harmless behaviour to instances where the disabled person may for example smash furniture or strike out blindly. Even when aggressive or violent behaviour is present it may vary in its extent, thus influencing the amount of danger the person is likely to encounter.

(viii) The frequency of attacks. Here, the care needs will be influenced by the pattern rather than the overall average frequency. For example, a person who has 6 or 7 attacks in one day followed by a week or more without any is likely to be at greater risk of danger than the person whose attacks are more evenly spaced, but where there is only one attack on an affected day. This is not to say that a person with a pattern of evenly spaced attacks will not require continual supervision: it will depend on the circumstances in which attacks occur, and on all the associated factors.

(ix) Whether the attacks occur only in bed, only when the person is up and about or both.

(x) Whether the person has received anti-convulsant drugs and, if so, whether they have reduced the frequency or severity of the attacks.

(xi) Whether the person ever injured himself or others during an attack and if so, how often, how recently and with what severity.

(xii) Whether the person has ever experienced status epilepticus. Status must be differentiated from serial epilepsy. Status is a series of attacks between which the person does not recover consciousness. 'Serial epilepsy' is a number of attacks following in quick succession but with at least partial recovery between attacks. Both are potentially serious, but if status is not arrested rapidly by appropriate treatment, there is a serious risk to life. [See para 14.8]

14.6 Care Needs:

14.6.1 The frequency of attacks is not in itself a sufficient guide. One person may have as many as 20 or 30 brief absences per day without significant interference with his lifestyle or work, whereas another with only one attack per day may be disabled because the attack is followed by a prolonged period of confusion during which he is a danger to himself or others. Equally the occurrence of a period of post-epileptic confusion cannot be decisive because one person may perform only purposeless harmless activity, whereas another may expose himself or others to danger. Nor is a history of injury decisive. People with epilepsy may suffer minor injury such as cuts or bruises, but it is rare for them to sustain serious injury. It is likewise uncommon for those who experience post-epileptic confusion or automatic behaviour to harm themselves or others.

14.6.2 The problems of epilepsy are largely related to supervision. The risks arising from epilepsy are likely to be very specific to the individual person and it is not possible to make assumptions from the effects of epilepsy in general. So, for example, a person who most days has one or more grand mal attacks without warning with severe convulsions in which he often sustains significant injury would be at substantial risk, at least by day. A person who has even more frequent 'absences' which do not interfere with work or social life and which have not led to injury faces little more danger than a person who does not suffer from epilepsy.

14.7 Mobility Considerations

14.7.1 A person with epilepsy which is not complicated by any other disabling condition is physically fit and should be capable of walking.

14.7.2 A person whose epilepsy is such that continual supervision by day is required to avoid danger to self or others will also most likely require supervision when walking out of doors.

14.7.3 If epilepsy is complicated by brain disease of some kind the situation may be different. [See para 14.9]

14.8 Status Epilepticus

14.8.1 This is a serious form of epilepsy in which seizures occur in such rapid succession that recovery of consciousness between the episodes does not occur. About 5% of people with epilepsy will have status epilepticus at some time. It is the most serious problem likely to be encountered in people with epilepsy and a significant number die during an attack.

14.8.2 When a person has been in status epilepticus the consequences will depend

on whether this was brought about by an avoidable precipitating factor such as sudden withdrawal of anticonvulsant drugs or overindulgence in alcohol. In these circumstances the risk of recurrence is small and can be disregarded. If the status was spontaneous then recurrence, with its attendant danger to life, cannot be excluded hence supervision by day and watching over at night is required. The risk of recurrence declines with the passage of time and returns to the baseline approximately three years from the date of the last episode.

14.8.3 Status epilepticus should be distinguished from serial epilepsy. In serial epilepsy, although the fits are very frequent, the person recovers consciousness in between attacks. It is not associated with the same risks as status epilepticus.

14.9 Complicating Factors

14.9.1 Epilepsy may be associated with, and a consequence of, brain disease such as head injury, cerebrovascular disease, tumour, degenerative and inflammatory conditions. The epilepsy and the complicating condition may not lead to a need for a great deal of attention or supervision when considered alone, whereas taken together, they may well do so.

14.10 Epilepsy in Parents of Young Children

14.10.1 A parent (mother or father) with epilepsy, who is caring for an infant or young child may pose a risk. In the event of an attack occurring without warning the parent may drop or fall upon the child. In cases where the risk of this happening is considerable, the parent may need supervision through the day. The risk becomes much less as the child becomes more independent.

14.10.2 It should be emphasized that it is the parent and not the child that needs supervision, to prevent substantial danger to the child.

14.11 Nocturnal (Night-time) Attacks

14.11.1 Once a person is in bed the risk of falling or otherwise sustaining injury in an attack is removed. Fear is often expressed that a person may choke or be smothered in an attack, but with a suitably firm pillow or sleeping without a pillow, the risk is remote. There may also be fear that following an attack in bed the person may get up and wander in a state of post epileptic automatism and so come to harm. When the type of attack experienced by the person makes this a possibility, danger can be obviated by taking suitable precautions.

14.11.2 It is rare for epilepsy to be so severe that the affected individual needs watching over at night.

14.12 Duration of Needs

14.12.1 If there has been a documented episode of spontaneous status epilepticus [see para 14.8] the risk of recurrence declines with the passage of time and returns to a stable state approximately three years from the date of the spontaneous episode, at which time reassessment of the needs may be considered.

14.12.2 There are a number of factors which can cause an alteration of the pattern of epilepsy, most notably drug treatment. If in an adult who requires continual supervision, at least by day, there has been no change in the pattern of epilepsy after two years, despite adjustment of his drug regime, then no further change is likely. If, however, a further modification of treatment is anticipated, the situation may well be different.

14.12.3 Where epilepsy in the parents of young children is considered to put the child at risk [para 14.10], the age of the child (children) at risk will assume critical importance, since the risk should become very substantially less as the child becomes increasingly independent and aware.

14.12.4 In persons with epilepsy whose mental competence is severely impaired such that they would be unable to assess their risk of danger in an epileptic attack, the requirement for supervision, at least by day, is likely to be life long.

14.13 Further Evidence:

14.13.1 As explained in para 14.5, establishing the needs of a person with epilepsy (particularly those related to a requirement for supervision to avoid danger to the affected person or others) is based on a number of features which characterize the nature, pattern, frequency and severity of the epileptic episodes. Evidence from the following sources may be helpful in determining needs in individual cases:

14.13.2 A specific disease-orientated factual report from a doctor who cares for the person will provide information on the diagnosis and type of epileptic attacks, their frequency and severity. This will be particularly helpful when, despite anticonvulsant treatment, the affected individual reports several attacks each week. Information from this source may also help to determine whether any change in the pattern of epilepsy can be expected.

14.13.3 When the diagnosis is not in doubt, assessment of the effects of the disability and the needs posed by it will be made easier by a factual report from a social worker or doctor who is conversant with the person's needs.

15. CERTAIN NEUROLOGICAL DISORDERS

15.1 Contents **Paragraph**

15.2 Multiple Sclerosis

15.2.1 Introduction

(i) Multiple sclerosis (MS) is a chronic, progressive, degenerative disease, characterized in the early stages by remissions and relapses in its clinical course leading in some, though not all cases, to persisting and progressive disablement. Destruction of areas of myelin (a substance surrounding nerve fibres which enables nerve impulses to travel along the fibre) throughout the brain and spinal cord is followed by scar formation [known as a "plaque"]. Nerve fibres eventually degenerate, leading to failure of transmission of nerve impulses. The optic nerves (the nerves to the eyes) and spinal cord in the neck region are most frequently affected.

(ii) Multiple sclerosis affects 30-80 people per 100,000 of population. The incidence of the disease rises throughout the second decade of life and is at its highest in the thirties. Slightly more women than men are affected. The disease rarely begins in people aged over 65.

15.2.2 Care Needs and Mobility Considerations

(i) The principal manifestations of MS are weakness of one or more limbs, spasticity (muscle rigidity or pronounced stiffness), muscle fatigue, unsteadiness of gait, and difficulties with speech. Tremor sufficient to interfere with the use of the upper limbs may develop. Loss of sensation may occur. Difficulty in bladder control is common, the person having to rush to reach the toilet in time and often being incontinent.

(ii) As the disease progresses walking may become increasingly difficult either because of weakness and spasticity or because of unsteadiness leading to

falls. This may be compounded by impaired vision and by weakness or tremor in the upper limbs which make the use of walking aids difficult or impossible. When walking, the severity of the muscle fatigue may result in the person's having to stop and rest frequently.

(iii) Short-term memory defects, impairment of speech, and mood swings are features of the more advanced stages of the condition.

(iv) The person may ultimately become chair or bed-bound. If this stage is reached there may be need for moving them frequently to prevent the occurrence of pressure sores.

15.2.3 Duration of Need

The average survival of patients from the time of diagnosis is 30 years. The average age at onset is 32 years, and so there is probably a slight reduction in overall life expectancy. However, course and effects of MS vary widely from one person to another and are unpredictable. Spontaneous remissions of varying length are common particularly in the early years of the disease, and in some instances appear to be life-long. Very rarely, multiple sclerosis takes a very rapid downhill course. However, the most common pattern is of frequently recurring relapses leading to chronic disability, dependency and complications. This process may take 20 years or more. Although the needs may change dramatically in the early years, if after two years there is a persistence or increase in needs, it is unlikely that there will be further improvements.

15.2.4 Further Evidence

A medical report may be helpful where the needs over any period of time are not clear because of the variable nature and progress of the disease.

15.3 Parkinson's Disease and Parkinsonism

15.3.1 Introduction

(i) Parkinson's disease (Parkinsonism) is a complex clinical syndrome associated with decreased concentration of a naturally occurring chemical, called dopamine, in certain parts of the brain. It is characterised by tremor, rigidity of muscles and difficulty in initiating movement.

(ii) Parkinson's disease affects 100 people per 100,000 of the population in the United Kingdom. Men and women are affected equally. Symptoms usually begin after the age of 50 years, but it can also affect younger people. After the age of 50, the incidence rises rapidly with increasing age. There are probably between 60,000 & 80,000 people suffering from Parkinson's disease in the United Kingdom at any time.

15.3.2 General

(i) The earliest manifestation is a general, barely perceptible, impairment of movement. This leads to loss of facial expression, less frequent gestures, slowing of gait and a gradual increase in the time taken to perform any task including dressing and eating. Tremor may appear, initially in the hands, and muscular rigidity develops. As the disease progresses these symptoms become more marked. Mobility is particularly affected. The gait becomes short stepped and shuffling. Involuntary, progressive acceleration of steps (festinating gait) may occur making it difficult to stop and predisposing to falls.

(ii) Alternatively the person may become rooted to the spot and unable to move. All tasks become more difficult especially those requiring fine movements of the fingers (tying shoe laces, doing up buttons, handling cutlery). Speech becomes slurred, weak and may be difficult to hear. At night the person may have difficulty turning in bed and so be unable to sleep because of pain and stiffness in the limbs. Mental function is not affected in the early stages, but in the late stages a proportion of sufferers become demented.

(iii) The management of Parkinsonism has been revolutionized by the introduction of the drug L-Dopa, and other drugs, which increase the level of dopamine in the brain. Drug treatment reduces symptoms in 80% of cases; people who untreated would have required considerable attention are enabled to remain independent for some years. However, as the disease progresses treatment may lose its effect, symptoms increase and independence is lost.

15.3.3 Care Needs

(i) Attention needs arise principally from muscle rigidity, paucity and slowness of movement and tremor. The amount of attention and/or supervision required by day will depend upon the severity of symptoms and the stage the disease has reached in the individual case. In people first diagnosed as suffering from Parkinson's disease who have just embarked upon an appropriate drug regimen, the beneficial response is usually achieved quickly, resulting in a dramatic improvement in the disablement and its associated needs. If after a year significant improvement has not occurred the situation is unlikely to change.

(ii) Those already in long-term receipt of drugs who still have substantial needs because of persisting muscle rigidity, tremor or slowness of movement, are unlikely to show any further beneficial response. People in this category will probably progressively deteriorate and have increasing needs throughout the remainder of their lives.

(iii) Independence is likely to be maintained by most sufferers in the early stages of the disease. As the disease progresses slowness of movement may make

it impossible to undertake household tasks. Later assistance may be required with dressing and undressing and cutting up food. In some cases the person continues those tasks unaided but takes an inordinate length of time. Feeding, including chewing and swallowing, may also become very slow. In these circumstances assistance is a reasonable requirement. In the later stages of the disease the need for attention during the day will normally increase. The likelihood of falls occurring, and the danger they pose, is an important factor in determining whether there is a need for supervision.

(iv) A requirement for attention at night is unlikely to be encountered until the later stages of the disease. Needs for attention at night arise in those who have difficulty in changing position in bed and in getting out of bed. The ability to use a portable urinal will also be impaired in those whose upper limb function is markedly affected by rigidity and tremor.

15.3.4 Mobility Considerations

The disturbances of gait and mobility described in paragraph 15.3.2 will be important considerations in the assessment of walking ability.

15.4 Motor Neurone Disease

15.4.1 Introduction

(i) This is a progressive chronic disease in which there is degeneration of motor nerve cells in the spinal cord. When the motor nerve cells degenerate the muscles supplied by them atrophy (become wasted) and lose the ability to contract. The cause of the disease is unknown. Its onset occurs most often between the ages of 40 and 60 years.

(ii) The first symptom is usually weakness of the hands and arms; finer movements are lost and articles are dropped. Later weakness of the muscles of the lower limbs develops and walking may be impaired. As the disorder progresses further, speech, swallowing and breathing are impaired. The course is usually progressive; over three to five years.

15.4.2 Care Needs and Mobility Considerations

(i) Attention needs will depend upon the extent of muscle weakness. In the early stages simple devices may help the person to maintain independence.

For example, special cutlery, velcro fasteners on clothing and ankle and foot supports are frequently used. But as the disease progresses weakness of muscles will be such that the person cannot attend to his bodily functions unaided during the day and walking may be severely limited. Progression of the disease eventually necessitates the use of a wheelchair. Likewise he may become unable to change position in bed during the night or use a urinal.

(ii) When respiratory muscles become involved, a tracheostomy and mechanical respiratory assistance may be used. In the advanced stages of this progressive disease there is a reasonable likelihood of death within 6 months.

15.5 Peripheral Neuropathy

15.5.1 The term peripheral neuropathy refers to damage to a nerve or nerves outside the brain and spinal cord. There are a wide variety of causes leading to variable degrees of loss of power and sensation in the area(s) of the body supplied by the damaged nerve(s).

15.5.2 Peripheral neuropathies can be divided into two broad categories depending on the distribution of involvement. The first group comprises damage to single peripheral nerves. Their effects alone are not likely to give rise to significant care or mobility needs. Secondly, there may be a diffuse and symmetrical disturbance of function due to the involvement of several nerves which can be called polyneuropathy (poly = many). In general, this results from causes that act diffusely, such as metabolic disturbances (ie. diabetes mellitus), toxins (poisons), deficiencies of certain vitamins etc. There are also hereditary polyneuropathies such as peroneal muscular atrophy. Because their effects are more widespread, polyneuropathies can cause significantly more disability and so the question of care and mobility needs is more likely to arise.

15.5.3 There are two polyneuropathies seen commonly. These are Guillain-Barre syndrome and the peripheral neuropathy that complicates diabetes mellitus. These are dealt with here.

15.6 Guillain-Barre Syndrome

15.6.1 Introduction

(i) This is an important form of peripheral neuropathy that affects many

peripheral nerves simultaneously. It usually develops suddenly. Often there is a history of a flu-like illness in the weeks before the onset of the neuropathy. Most cases recover satisfactorily within a few weeks or months. Very rarely it may lead to rapid and profound disability. Although the vast majority of people with this condition recover completely, a small percentage are left with a widely variable degree of permanent paralysis.

(ii) The condition usually affects the nerves that control muscles, causing muscle weakness. The distribution and severity of the weakness is variable and gives rise to differing types of disability. For example, if the nerves supplying the muscles of the hands are affected a person will have problems with activities needing good manual dexterity. On the other hand, a person in whom the nerves supplying the muscles of the trunk and legs are affected will have difficulty getting up from a chair and getting about and is therefore likely to need considerably more help in day to day activities. In the rare severe case the respiratory muscles are affected and the person may well need mechanical support for breathing for some time while the nerves recover.

15.6.2. Care Needs and Mobility Considerations

(i) In most cases complete or almost complete recovery will occur quickly and any care or mobility needs are unlikely to occur for more than a few weeks or months. In those cases where there is persisting weakness, the degree of disability is very variable indeed. This may range from some help being needed for a few minutes morning and evening when dressing to, very rarely, severe disability not unlike that of a person with paraplegia or tetraplegia. [Chapter 18]. As the intellect is not affected in cases of peripheral neuropathy, it is unlikely that there will be a need for supervision.

(ii) As with care needs, mobility problems will be very variable. The majority will need no help of significance but a few will have great difficulty walking for some several months or more after the onset of the condition.

15.6.3 Duration of Need

As most cases recover quickly it is unlikely that significant disability will persist for more than six months. However, in the small number of cases where it is clear that severe disability is persisting it is possible that a degree of further recovery may occur in a year or so. The chance of further recovery is then remote.

15.6.4 Further Evidence

Most people with severe Guillain Barre syndrome will have been seen at hospital where the diagnosis should have been made. A factual report from the hospital will help to establish the severity of the original illness and the likely duration of disability if this is not clear. If there has not been a hospital admission this may raise doubt about the exact diagnosis and an

EMP report should be helpful.

15.7 Peripheral Neuropathy of Diabetes Mellitus

15.7.1 Introduction

(i) About 15% of people with diabetes develop a significant degree of peripheral neuropathy. This is usually a symmetrical sensory polyneuropathy which can have important consequences since the loss of sensation leads to injury and the diabetes causes problems with healing. Commonly, the sensory neuropathy is mild, giving rise to numbness and tingling in the toes and feet and, less commonly, in the fingers. This does not normally give rise to significant problems. More rarely a severe sensory neuropathy develops which is associated with the loss of pain sense. Damage to the joints of the toes and the ankles can occur, leading to degeneration of these joints. Minor injuries go unnoticed and because of poor healing small cuts can develop into large ulcers which become infected. In many cases the situation is complicated by peripheral vascular disease and often the only successful treatment is amputation of the foot or even the leg.

15.7.2 Care Needs and Mobility Considerations

With the mild degree of sensory impairment usually seen there should be no significant increase in care and mobility needs on account of the neuropathy. With the more severe form there will be obvious problems with mobility and, depending on the age and capabilities of the individual, there may also be care needs. If there are significant needs these are likely to be permanent.

15.7.3 Further Evidence

The degree of disability caused by the neuropathy should be fairly clear. If it is not, a factual report from the doctor taking care of the person (GP or hospital doctor) should provide the additional information needed.

15.8 Huntington's Disease

15.8.1 Introduction

(i) Huntington's disease is an inherited condition, occurring in 1 per 20,000 people (ie. about 3,000 in the United Kingdom). Children of an affected individual have a 50% chance of also developing the disease. Its onset is usually in middle life, between the ages of 30 and 50, although it can

present as progressive dystonia (rigidity) in the teens. It is a progressive disease leading inevitably to severe disability and death. Death occurs on average 14 years after the onset.

(ii) The condition is due to a slowly progressive destruction of the cells of the brain, and is characterised by the gradual onset of uncontrollable movements (chorea) of either an abrupt jerking, or slow writhing nature; together with progressive loss of mental function. The initial symptoms are frequently of a change of personality and behaviour, but chorea may be the first sign. As the disease progresses dementia [See Chapter 21] becomes more obvious and the chorea more severe. The person has increasing difficulty with walking, with use of the hands and with speech. Gait is impaired by uncontrollable lurching and staggering. Attempts to pick up a pen or cup of tea set off wild, uncontrolled lunges. At this stage insight is lost, as is awareness of dangers, and behavioural problems increase. In the final stages many people develop increasing muscle rigidity and loss of movement. This leaves the person totally helpless and bed-ridden.

15.8.2 Care Needs and Mobility Considerations

(i) These will depend on the stage of the disease reached and the particular features shown by the affected individual. In the very early stages of Huntington's disease when the chorea is mild and insight is retained there may be few problems with day-to-day activities or with walking. As the chorea worsens, walking becomes more and more difficult as do many everyday activities such as dressing, eating, drinking and managing at the toilet. If dementia is a significant feature then there will be a serious risk of danger and a need for supervision.

(ii) Disability is relentlessly progressive, and in the final stages when the person is emaciated and bed-ridden a considerable amount of attention will be needed both by day and by night.

15.8.3 Further Evidence

In most instances the care and mobility needs should be clear. Factual reports may help in those early cases where, either the diagnosis is not clear, or where there may be a significant suicide risk. In these early stages when insight is retained, with an awareness of what may be in store, depression is not uncommon and suicide is a risk. In the first instance a hospital factual report should be obtained, but if the person has not attended hospital, the GP may well be able to confirm the presence of the disease in previous generations of the family.

15.9 Myasthenia Gravis

15.9.1 Introduction

(i) Myasthenia gravis is characterised by rapid and extreme tiredness of the muscles. Thus, whilst muscle power may initially be strong, it rapidly fades with sustained effort. The disease usually develops in early adult life, but may start in childhood or even late in life. It is twice as common in women as in men.

(ii) The muscles of the face, throat and neck are almost invariably the first and most seriously affected. The condition commonly presents with drooping of the eyelids and double vision. Typically, symptoms first appear in the evening when the person is tired, and disappear after a night's sleep. There may be difficulty swallowing and chewing, complaints that worsen during the course of a meal. Speech may also be affected.

(iii) The muscles around the shoulders are also frequently involved and it is not uncommon for the muscles of the hips and thighs to be affected. The muscles of respiration may also be affected leading to the need for assistance with breathing.

(iv) Although the disease is generally progressive, there tend to be remissions and relapses. In some cases remission is complete and long lasting, and these people will not have significant care and mobility problems. In all but the later more severe stages of the disease, treatment is highly effective and may result in there being neither care needs nor problems with walking.

15.9.2 Care Needs and Mobility Considerations

(i) These will depend on the severity of the disease, the muscle groups affected and response to treatment. In mild cases, particularly those affecting the muscles of the face and throat alone there may be no need for any help of significance. It may be necessary to adapt the lifestyle somewhat to cope with the increased fatiguability at the end of the day but otherwise it should be possible to lead a normal life.

(ii) Those whose shoulder muscles are affected may need help lifting heavy objects. They may later need help at the beginning and end of the day with dressing, washing and bathing. In severe cases they may be able to do very little with their arms and need a considerable amount of help both by day and at night.

(iii) Those whose hip and thigh muscles are affected will have difficulty getting up from a chair or bed, and mobility will be reduced. In most instances the upper limbs will also be affected adding to the difficulty.

(iv) If the muscles of respiration are affected the person may have difficulty

breathing, in some instances to a degree sufficient to warrant mechanical assistance. In this situation the care and mobility needs will be considerable.

(v) Insofar as myasthenia gravis does not lead to intellectual impairment, supervisory needs are not normally a feature of the disease. Only in its advanced stages is there likely to be a tendency to fall, by which time attention needs will predominate.

15.9.3 Duration of Need

Most remissions occur in the first five years of the disease. If at any time disability is found to be severe and unresponsive to drug treatment, particularly if the respiratory muscles are involved, there is unlikely to be significant improvement in the future.

15.9.4 Further Evidence

In most cases the level of disability and its duration will be clear. If it is not, a report from the GP or hospital should provide the necessary additional information. Since response to specific treatment with certain drugs is usually good, factual information should be sought on how well the person is managed with appropriate treatments

15.10 Meniere's Disease

15.10.1 Introduction

(i) This is a disease of the inner ear characterised by attacks of vertigo (dizziness), nausea and vomiting, associated with tinnitus (ringing in the ear) and increasing deafness. It can occur at any age but usually starts in the 4th or 5th decades.

(ii) Although attacks may be extremely incapacitating at the time, it is uncommon for them to last for more than a few hours at a time or to occur frequently for more than a few weeks at a time. The overall care and mobility needs will usually be slight.

(iii) The first symptoms usually noticed are deafness and tinnitus; but there may be vague unsteadiness, hearing difficulties, slight nausea or a feeling of pressure in the head. These normally affect one ear only but may progress to involve both. The attacks of vertigo may begin abruptly but are normally preceded by an intensification of the tinnitus. This or other warnings usually gives the sufferer time to sit or lie down so falls are unusual. There is usually no precipitating event for the attacks and they may occur during sleep.

(iv) The attacks usually last between 15 minutes and 2 hours during which time it is unusual for there to be any need for attention or supervision. The attacks can be frightening so reassurance may be necessary, but the person

is unlikely to be in any danger. There may be long periods of freedom from attacks and in those cases that do progress the attacks may cease or eventually diminish with increasing deafness. Some persons may be left with some disturbance of balance.

15.10.2 Care Needs and Mobility Considerations

Because the attacks usually occur in clusters with weeks or months in between, any care and mobility needs that may arise are intermittent and short-lived. At most there may be a need for help for a few weeks at a time. For the periods free from attacks there will be no attendance need. The person usually gets warning of an attack. The affected person would not usually have any mobility problems.

15.10.3 Further Evidence

If there appear to be care and mobility needs in excess of those mentioned above, a report should be obtained from the GP or any hospital the person is attending.

15.11 Migraine

15.11.1 This condition is characterised by periodic headaches, which are typically one-sided and are often associated with visual disturbances and vomiting. It is more common amongst women and tends to run in families. The condition usually starts after puberty and continues until late middle life when the attacks tend to lessen. Even for those who suffer severe attacks, their intermittent nature means that the overall needs for assistance are slight. There should be no need for assistance from another person during such an attack. Reassurance may be required but there should be no significant danger. The occurrence of migraine should not result in any mobility needs.

15.11.2 Further Evidence

If there appear to be significant care or mobility needs a factual report should be obtained from the GP.

15.12 Poliomyelitis

15.12.1 Introduction

(i) Poliomyelitis is a disease caused by a virus. Whilst the disease has been virtually eliminated from most developed countries by immunisation, it still occasionally occurs in people who have not been immunised. The vast majority of those infected with poliomyelitis have no apparent symptoms at all and recovery is complete. However a minority develop paralytic poliomyelitis. Most of those who have needs resulting from poliomyelitis will have been infected many years ago, and their problems will have been complicated by the natural ageing process.

(ii) The paralytic form of the disease leads to asymmetric (uneven) paralysis without loss of sensation. The paralysis may affect only a few muscle groups or alternatively many. About half of those with paralysis will recover completely, but the remainder will have residual long term disability ranging from mild to severe. Regular physiotherapy and a regime of personal management will reduce long term deterioration.

(iii) Later in life, as ageing results in nerve cell loss, there may be a slow deterioration as the original problems resulting from poliomyelitis are aggravated by the normal ageing process. Muscle wasting may increase and, for example, walking may become impossible. Lung capacity may decrease, and in extreme cases lead to a requirement for breathing assistance during the day or throughout the night.

(iv) In those who have had paralytic poliomyelitis, the daily living and mobility problems are caused by secondary impairments as well as the paralysis itself. Asymmetric growth, particularly when the disease has been contracted in childhood, may cause problems; spinal deformities may occur if the trunk muscles are affected asymmetrically, possibly resulting in poor balance when sitting and reduced lung capacity; contractures of joints may occur from prolonged poor positioning; arthritis may develop as a result of abnormal strain on joints unaffected by the condition; poor circulation and loss of muscle bulk can result in extreme coldness of limbs, which may not be helped by the wearing of extra clothing as this may further reduce movement; obesity may develop through loss of the ability to exercise.

15.12.2 Care Needs and Mobility Considerations

(i) The care and mobility needs resulting from paralysis are described in Chapter 5.

(ii) The care and mobility needs resulting from disabilities due to the secondary impairments will vary considerably, depending on the impairments a person has and the extent to which they have developed. Cases need to be treated individually, although guidance may be found for arthritis in Chapter 6 and some of the details on spinal injury in Chapter 18 may be relevant.

15.12.3 Duration of Needs

Once established, the paralysis is permanent. In the first year following

onset, the person may learn new ways of accomplishing tasks, thus increasing independence. The level of independence attained may then be maintained for many years. Thereafter, it is likely that needs will increase with age in those who have established paralytic poliomyelitis.

15.12.4 Further Evidence

If there is difficulty in deciding the degree of a person's disability and the amount of attention or supervision required, a report from a GP or an examining medical practitioner (EMP) should be obtained.

16. THE CHRONIC FATIGUE SYNDROME

16.1 Contents

16.2 Introduction

16.2.1 There is a spectrum of conditions where the prominent symptoms are fatigue, both physical and psychological, which may affect both physical and psychological functioning. At one end are people whose clinical condition is indistinguishable from that of depressive illness. At the other are people with fatigue in the apparent absence of any readily identifiable psychiatric disorder.

16.2.2 A number of names, including post-viral fatigue syndrome and myalgic encephalomyelitis (ME), have been used to describe one of these conditions. More recently the term Chronic Fatigue Syndrome (CFS) has been universally adopted.

16.2.3 There is controversy over the causes of CFS. This is particularly over whether it has a physical basis (related to a persistent viral infection or disturbance of the immune system or some other cause), or is a purely psychological disorder, or is due to a combination of factors, such as occurs in other conditions [see Chapter 19]. Recent evidence (yet to be substantiated) suggested a functional disturbance in the brain. However, the significance of these findings is not yet clear.

16.3 Clinical Manifestations

16.3.1 There are some cases where the condition appears to follow a viral illness (e.g., influenza, glandular fever). There are no objective clinical or laboratory tests for CFS, and diagnosis can be difficult.

16.3.2 In some cases of CFS, subjectively prolonged recovery time and marked fluctuations of symptoms can be encountered. In severe cases, extreme physical and mental fatigue with prolonged recovery time and marked fluctuation in symptoms can be characteristic. However, neither prolonged recovery time after effort nor marked fluctuations are unique to CFS.

16.3.3 There is wide variation between individuals in the nature and severity of symptoms. These can include muscle pain and exhaustion when attending to

normal functions such as washing or dressing, and can be accompanied by a variety of symptoms affecting balance, concentration and sleep disturbance. In more severe cases the symptoms can persist for several years, and in a small minority of people there may be a state of total dependency.

16.4 Management

16.4.1 There is no specific drug treatment. Anti-depressants are helpful for clinical depression, and may be used in small doses as symptomatic treatment for those who have muscle pain and sleep disturbances. Cognitive behaviour therapy has been shown to promote recovery from CFS in some people. Among other things it aims to help people re-evaluate their understanding of the illness and to adopt more effective coping behaviours.

16.4.2 From the physical standpoint, the aim is to find and maintain the right balance between rest and activity (known as pacing). Reduced activity is important in the early phase of the illness and during a relapse. Following this, a baseline of sustainable physical and mental activity should be determined and every effort made to maintain and extend this. Careful pacing with gradually increasing physical and mental activity is the goal. Total rest is counterproductive and leads to a vicious circle of progressive muscle weakness and wasting.

16.4.3 A concerted approach to treatment is required, which should address physical, psychological, social and employment factors.

16.5 Care Needs

16.5.1 There may be wide day-to-day variation in the severity of symptoms. It is necessary to discover what a person can do on a bad day as well as on a good day, and to establish how often each type of day occurs. A satisfactory level of physical and mental activity is one which can be sustained day after day without leading to a prolonged increase in symptoms, and not the amount managed only on a good day.

16.5.2 Whilst attending to bodily functions may take longer than normal, the majority of people with CFS appear to manage these unaided most of the time. Matters such as food preparation, shopping and household tasks may appear to cause problems for people with CFS. In those who have been immobile for long periods, physical help from another person may be required. A few people may be bed or wheelchair bound and may need help with personal care and to transfer on and off toilets etc. In a minority there is severe disablement and a state of high dependency.

16.5.3 Objective studies of muscle function may fail to reveal abnormal fatigue or weakness. However, when muscle weakness is clinically evident, this may indicate secondary disuse atrophy (wasting), and be an indicator of likely care needs. Severe fatigue in the absence of any objective evidence of muscle wasting

or weakness does not necessarily imply a definite and exclusively psychological cause. Furthermore, in individual cases, causes for severe fatigue which have not yet been diagnosed may be present.

16.6 Mobility Considerations

16.6.1 The majority of those with CFS are mobile, although they may walk rather more slowly than normal. The difficulty in walking is the result of fatigue, but may also be, in part, due to muscle pain, loss of balance, or weakness of muscles resulting from disuse. Patterns of walking for which no neurological cause can be identified may be seen, even in the absence of muscle wasting or other specific cause of abnormal gait. Muscle symptoms adversely affecting mobility may continue beyond the actual period of exercise. Physical disability may be influenced by the psychological state of the person. In those with the severest disability there is an increased likelihood of treatable psychological disorders and mental health problems.

16.7 Duration of Need

16.7.1 There is wide variation in both severity and duration of the illness. In people who suffer from fatigue, muscle symptoms and a lack of well-being following a viral illness such as influenza or glandular fever, recovery can be expected within a few weeks or months. Of those with established CFS, the majority can be expected to show a substantial improvement over time. There are others in whom the symptoms of fatigue last for much longer and may pursue a relapsing course. The persistence of fatigue may occur both in severe and milder forms of the condition.

16.8 Further Evidence

16.8.1 A report, based on a home visit from an examining medical practitioner (EMP), may help in determining the care and mobility needs. The report should state whether the accepted criteria for the diagnosis of CFS have been met, identify the severity, variability and fluctuation of the condition and estimate the relative predominance of physical and psychological factors in the case. A report should request an explanation of any discrepancy between the examination findings and the information provided on the claim form. Indication of prognosis and details of past and present management and treatment should also be requested. A factual report from a GP, hospital or other relevant specialist may also be helpful.

17. DIABETES MELLITUS IN ADULTS

17.1 Contents

Related conditions considered in other chapters

17.2 Introduction

17.2.1 Diabetes mellitus is a common condition affecting about 2 per 1000 of those under 20 and 3 per cent of the adult population. However in those aged over 60 years up to 5% of the population may have this disease. It is treated by diet, oral hypoglycaemic drugs (which lower high blood sugar levels) or injections of insulin.

17.2.2 People with uncomplicated diabetes mellitus do not normally need help with personal care. They are taught to test their own urine and blood sugar and to inject their own insulin. In persons with uncomplicated disease adherence to a special diet does not give rise to a need for attention. However where there is visual impairment, severe learning disability, or dementia there will be a need for help with testing urine and blood, and for injecting insulin.

17.3 Care Needs

17.3.1 Loss of Vision and Diabetes Mellitus

People with diabetes mellitus may develop diabetic retinopathy (disease of the back of the eye where the image is formed) or cataract (opacities in the lens of the eye); in addition they may have severe loss of vision or colour appreciation from causes unrelated to the diabetes. If visual impairment results, then the needs will be similar to those of other visually impaired people. In addition testing of urine and blood will have to be performed by another person. When the person with insulin-dependent diabetes and impaired vision also requires insulin injections to be prepared and/or given by another person the attention required will need to be given several times throughout the day. The use of "pen" syringes should not affect this need for attention, because visual control is still necessary to avoid mis-alignment.

17.3.2 Co-existing Learning Disabilities or Impairment of Brain Function in People with Diabetes Mellitus

Persons with learning disabilities [see also Chapter 20] may not be able to undertake their own monitoring and administration of insulin. The demanding nature of insulin therapy may cause problems for persons with learning disabilities who may, otherwise, be able to cope with, for example, simple oral medication. A person with such learning disabilities may be able to hold down a simple job and cope adequately with day-to-day activities but be unable to manage the complexities of insulin therapy which requires careful monitoring, adjustment of dose and recognition of hypoglycaemic episodes. In the same way people with dementia [see Chapter 21] may also find the complexities of insulin therapy daunting and be unable to manage their own monitoring and insulin administration without the assistance of another person. In these circumstances where there is substantial impairment of normal brain function, whether this is due to learning disabilities or dementia, the level and frequency of attention required may be similar to that already described for persons with visual impairment [see para. 17.3.1].

17.4 Complications of Diabetes Mellitus

17.4.1 Although the prognosis for patients with diabetes mellitus has greatly improved, they are still at risk of a number of complications, which include diseases of the blood vessels to the heart, brain or legs [see Chapters 11, 12 and 13]; neuropathy (poorly functioning nerve pathways -Chapter 15.5) and kidney disorders. Attendance needs may arise in relation to these, each case being considered on its merits in relation to the attention required. Some people with diabetes may become depressed or resentful of their condition, and may find it difficult to co-operate fully with treatment.

17.5 Hypoglycaemia [low blood sugar levels].

17.5.1 Hypoglycaemia means an abnormally low blood sugar concentration. The manifestations of hypoglycaemia vary from one patient to another but tend to be the same with each reaction for the same person, which makes it more easily recognisable by those who suffer from these episodes. Mild, early symptoms and signs of a drop in blood sugar levels include sweating, pallor, shakiness, feelings of hunger and a feeling of apprehension. More advanced symptoms of faintness or dizziness, blurring of vision and uncoordinated movements occur with further falls in blood sugar levels. Rarely there may be confusion and eventual loss of consciousness. Hypoglycaemia is just one of the causes of loss of consciousness (coma) in diabetes. The other causes, the most common of which is known as ketoacidosis, whilst having very serious consequences, do not develop as rapidly as hypoglycaemia and should not normally lead to a need for continual supervision.

17.5.2 People with diabetes mellitus who are receiving insulin or certain oral hypoglycaemic drugs are liable to develop hypoglycaemia. They should be able to recognise the symptoms of hypoglycaemia during the day and take appropriate preventative action; such as taking a sugar solution, sweetened fruit juice, or some honey or sugar with a glass of water. However there are

some people with long-standing diabetes, often in the 40-60 years age group, with poor awareness of the onset of hypoglycaemia. These people may not be able to recognise an impending attack. Rarely the severity of a hypoglycaemic attack may require admission to hospital and/or the administration of a drug by injection which elevates the blood sugar level.

17.5.3 Prevention of hypoglycaemia during the night may uncommonly require the person to waken and take food or drink. The use of an alarm makes assistance from another person unnecessary. Even when there is some other disablement precluding the person getting food and drink, this may be left within reach by the bed usually making night attention unnecessary. However in those persons where there is evidence of a persisting lack of awareness of the onset of hypoglycaemia they may already be hypoglycaemic when a night alarm sounds and thus be unable to take appropriate action.

17.5.4 People with learning difficulties and diabetes mellitus who cannot recognise hypoglycaemic symptoms by day and take the necessary action, may require someone to supervise them by day depending upon the severity of the learning difficulties. Rarely such people may need to take food and drink at night, if so they may need attention in order to remind them to do so [see also para 17.3.2].

17.6 Further Evidence

17.6.1 When in some affected individuals, despite precautions, hypoglycaemic attacks resulting in coma or hospital admissions have occurred, a report from the consultant physician who looks after them may greatly assist in clarifying the severity and frequency of these episodes and whether there is a persisting lack of appreciation of the onset of hypoglycaemia, describing how they are managed and providing a prognosis.

17.6.2 The following factors are important in determining the severity and frequency of these episodes and the nature and extent of any danger arising from them:

(i) The level of danger arising from an attack is dependent on how low the blood sugar has become. However, any hypoglycaemic episode which severely impairs the level of consciousness may be potentially dangerous. The results of laboratory tests measuring the sugar level during attacks will therefore assist in evaluating the risk of danger.

(ii) If there is a history of hypoglycaemia:

(a) The frequency of attacks requiring admission to hospital or treatment by injection, by day and night.

(b) Whether or not these attacks can be avoided or prevented.

(c) Whether or not there is any warning of attacks, particularly

at night.

(d) Advice which has been given to the person to control these attacks.

17.7 Mobility Considerations

17.7.1 The ability to walk is not impaired in persons with uncomplicated diabetes mellitus. However, in some people with long-standing disease complicated by reduced blood flow in blood vessels narrowed by vascular disease [see Chapter 13] or in those with poorly functioning nerve pathways in the legs [see Chapter 15.5], walking may be restricted either by pain in the legs brought on by exercise or by weakness of leg muscles. In some cases amputation of one or both legs may have occurred and adjustment to artificial limbs may not always be successful. Diabetes may also give rise to kidney failure [see Chapter 23] in a substantial number of affected individuals. It is commonly associated with visual impairment and lower limb problems.

18. SPINAL INJURY

18.1 Contents **Paragraph**

18.2 Introduction

18.2.1 Damage to the spinal cord results in paralysis and loss of sensation below the level at which the cord has been injured; together with loss of ability to control bladder and bowels. The type of paralysis depends on the level of the injury.

18.2.2 **Paraplegia**, which is paralysis involving both lower limbs, results from damage to the thoracic (middle) or lumbar (lower) sections of the cord. Part or all of the trunk may also be affected.

18.2.3 **Tetraplegia**, also called **quadriplegia**, is paralysis involving all four limbs. It results from damage at the cervical (neck) level. The whole trunk may also be affected.

18.2.4 Paraplegia is a major disability, but pioneering work at the Spinal Injuries Centre, Stoke Mandeville, during the 1939-45 war showed that rehabilitation is possible in the great majority of cases to the point of independence, in a wheelchair and with suitably adapted living accommodation, in the activities of daily living.

18.3 Care Needs

18.3.1 Rehabilitation of the person with **paraplegia** depends on the person learning to transfer from bed to wheelchair or other surface at a similar level. The ability to do so requires normal function in the upper limbs. With the use of appropriate aids, the person can then swing the lower part of the trunk and lower limbs to effect the transfer. The ability to balance whilst sitting, and to lean short distances forward, background, and sideways, may also be developed during the course of rehabilitation.

18.3.2 Because of the loss of sensation the person is constantly exposed to a risk of damage to the skin and to the development of pressure sores. He is trained to avoid this danger by regularly changing position both by day and by night.

18.3.3 Loss of bladder and bowel control is dealt with in various ways. Mechanical pressure exerted by the person on the lower abdomen may be used to empty the bladder at pre-determined intervals. More commonly, self-catheterisation

is employed. Alternatively, in men a penile sheath may be connected to a urinal strapped to the thigh. In women, waterproof pants with an absorbent pad are often worn. Emptying of the bowel may be assisted by use of suppositories or enemas, or by manual evacuation.

18.3.4 A person with traumatic paraplegia who has normal function in the upper limbs would therefore usually be expected to attain a considerable degree of independence in attending to bodily functions. However, a significant amount of help may still be needed with tasks which are performed at the beginning and end of the day.

18.3.5 As far as night is concerned, a person who, with suitable aids, can turn himself in bed should be able to do so at prescribed intervals by setting an alarm. If he cannot turn unaided, attention will be required.

18.3.6 On occasion a seemingly independent person does in fact require assistance. For example, repeated breakdown of the skin with the formation of pressure sores, or repeated urinary infection, may indicate that though the person appears to be coping with his bodily functions, his care is not adequate and he requires help from another person.

18.3.7 There are factors which may prevent successful rehabilitation. The majority of persons with traumatic paraplegia are young, previously healthy and possess the considerable and sustained motivation necessary for successful rehabilitation. Older persons may lack the requisite strength and stamina. Young persons who at the time of their accident suffer significant brain as well as spinal damage, may not be able to achieve independence. Some young persons without brain damage may be unable to adjust psychologically to the radical change in their entire way of life, and in these circumstances continued assistance may be necessary.

18.3.8 In persons with **tetraplegia**, the upper limbs are also weak to a greater or lesser extent, and therefore cannot be used to effect transfers from bed to wheelchair, to change position in bed, or to cope with bodily functions. Persons with tetraplegia will therefore require a great deal of help both by day and by night.

18.4 Mobility Considerations

18.4.1 The person with a spinal injury resulting in paraplegia or tetraplegia is unable to walk.

18.5 Duration of Needs

18.5.1 Rehabilitation in respect of care needs, during which the affected person has to master all the new tasks which have to be learned, commonly takes about two years following the injury. During the rehabilitation phase, there is likely to be a need for considerable help, at least by day. At the end this period a well-adjusted, well-rehabilitated person with paraplegia should be able to perform most, or all, of these tasks without the assistance of another person, although assistance may still be required with tasks at the beginning and end of the day.

18.5.2 The care needs of a person with tetraplegia will be ongoing.

18.5.3 A person with paraplegia or tetraplegia resulting from an injury which severs the spinal cord will remain permanently unable to walk.

18.6 Further Evidence

18.6.1 In cases in which there is difficulty in deciding the degree of a person's disability and what help is needed, a report from the spinal injuries unit with which the person has regular contact, would be helpful.

18.7 Paraplegia From Other Causes

18.7.1 The effects of paraplegia which is not of traumatic origin will depend on the cause. In conditions which, when successfully treated, do not lead to progressive disability, the care and mobility needs will be similar to those arising from traumatic paraplegia. Where paraplegia is due to progressive disease such as cancer, there will usually be progressive deterioration with accompanying high dependency on help from others.

18.7.2 In persons with paraplegia not due to trauma, the cause of the condition will have to be identified, since this will give an indication of the likely care needs and their duration. If further evidence on this point is required, it should be sought from the GP or from a consultant at the hospital which the person is attending.

19. MENTAL HEALTH PROBLEMS

19.1 Contents: **Paragraph**

19.2

Introduction

19.2.1 Depending on the way in which mental health problems are defined 10% of the population, at any one time, can be said to be affected by some kind of mental health problem. Mental distress is experienced by many people without necessarily having an exact mental health diagnosis and such people often go unrecognised and untreated.

19.2.2 Only a small minority of people with mental health problems are referred to psychiatric services, and these are typically people with severe or chronic forms of mental illness. Most people with the more severe mental health problems are rarely seen by mental health professionals until late in the episode. Indeed the majority of people with mental health problems are managed entirely by the general practitioner or may never reach a health professional. Many of these people are frequently assessed initially, and usually treated in the general (ie. non-psychiatric) setting.

19.2.3 Mental health problems may give rise to attendance needs. These are usually in the form of supervision/watching-over, but severe mental illness may also give rise to needs for attention in connection with bodily functions. Mobility needs may also occur. In people with mental distress there may be combinations of disabilities, including a mix of physical and mental disabilities. The combination of these effects needs to be taken into consideration when assessing care needs.

19.2.4 Unfortunately, an unwarranted stigma is often attached to a diagnosis of mental illness despite greater understanding in the community in recent years. Some people with mental health problems, particularly depression, therefore may tend to minimise the mental health component and maximise symptoms that relate to physical disability. Moreover, a large number of physical disorders have psychological components. Both of these components need recognition and assessment in the proper determination of care needs.

19.3 Classification

19.3.1 Various forms of mental illness have been recognised in almost every culture in the world. Mental disorders encompass a very wide range of diverse illnesses which have been given a variety of different diagnostic labels. Although the nature and severity of disability in the individual case are of paramount importance in determining the nature and level of care needs, rather than the exact diagnosis of the condition giving rise to the disability, the following broad classification of mental health disorders greatly assists in predicting the likely range and extent of care needs which may be associated with them:

The Psychoses **(19.4)**

- **Schizophrenia** **(19.5)**
- **Severe Depressive Disorder, Manic-depressive psychosis (Bipolar Depression)** **(19.6)**

The Neuroses **(19.7)**

- **Generalised Anxiety Disorder** **(19.7.3)**
- **Panic Disorder** **(19.7.4)**
- **Phobic Anxiety Disorders** **(19.7.5)**
- **Obsessive - Compulsive Disorder** **(19.7.6)**
- **Mild Depressive Disorder** **(19.7.7)**
- **The Personality Disorders** **(19.8)**
- **Dissociative (and Conversion) Disorders, Hysteria and Somatoform Disorders** **(19.9)**

The Dementias **(Chapter 21)**

Drugs and Alcohol **(Chapter 22)**
Eating Disorders **(Chapter 23)**

19.3.2 Leaving aside the dementias which are most common in the elderly, and are separately described in Chapter 21; and alcohol and drugs abuse, and eating disorders which are covered in Chapters 22 and 23 respectively, this chapter will concentrate on the mental disorders listed above [para 19.3.1].

Factitious disorders and malingering are also dealt with for convenience at the end of this chapter [Paragraphs 19.10 and 19.11]. However these disorders involve a conscious and deliberate attempt to feign illness and its symptoms and are thus not conventionally considered to be mental health disorders

19.4 The Psychoses

Psychoses are severe forms of mental illness which affect the whole personality and

are used to describe sets of symptoms which commonly go together, create a severe burden on the affected person, and frequently give rise to major disturbances of thinking and behaviour which may pose considerable attendance needs. They can affect people of any level of intelligence, most of whom will have apparently developed normally, with no intellectual problems, during childhood and adult life until the onset of the mental condition. Psychoses affect thought, mood or behaviour singly or in combination. As a result many people with a psychotic condition will have high levels of physical and intellectual abilities but have difficulties in using them because of anxiety, lack of concentration, or apathy, etc, to an extent that they have problems coping with general daily tasks. Typically a person affected by a psychotic illness loses touch with reality, has disordered thought processes, delusions (false beliefs) and/or hallucinations (eg seeing non-existent things or hearing non-existent voices). They frequently lack insight (ie. they are not aware that they are ill). Some may be on medication which leaves them forgetful or drowsy or affects their bodily functions. The two most common psychoses are schizophrenia and manic-depressive psychosis.

19.5 Schizophrenia

19.5.1 Introduction

(i) Schizophrenia is one of the most serious forms of severe mental illness. Its lifetime prevalence is nearly 1%, its annual incidence is about 10-15 cases per 100,000 people in the population and the average general practitioner probably cares for 10-20 people with schizophrenia. Around 8% of people with schizophrenia are managed entirely by their general practitioner without referral to psychiatric services.

(ii) Contrary to continuing popular belief a person affected by schizophrenia does not have a split or multiple personality but has a general disturbance of thought processes and a disruption of the personality. The condition has profound effects not just on those affected, but also on their families and friends.

(iii) Onset in men is usually before the age of 30. In women the onset is a little later, by some four years.

19.5.2 Clinical Features

(i) People with schizophrenia may demonstrate positive symptoms of psychosis such as delusions, hallucinations and thought disorder, or negative symptoms such as social withdrawal, limited and slow thought, blunted emotions, loss of initiative and the sense of enjoyment. Some people show both positive and negative features to varying extents.

(ii) People with **thought disorder** may complain of poor concentration or of their mind being blocked or emptied (thought block). They may stop in mid speech in a perplexed fashion with continuing incoherent and disconnected speech. They may have difficulty following a train of thought

to a logical conclusion, with individual thoughts having only a very peripheral connection to each other.

(iii) **Hallucinations** are false perceptions in any of the senses. The person experiences a seemingly real voice or sound or smell, for example, although nothing has actually occurred. A common clinical feature of schizophrenia is that the affected person experiences voices talking about them or telling them to do something.

(iv) **Delusions** are false beliefs held with absolute certainty, dominating the person's mind, which have no apparent basis in reality, for example a false belief of persecution.

(v) The early stages of schizophrenia can vary considerably. A typical presentation is that a family expresses concern that a personality has changed or even makes a mistaken assumption that the causes of the observed changes are due to substance (drug) abuse. A decline in personal hygiene, depressive symptoms, loss of friends or jobs, all for no good reason, are commonly encountered. About one in ten people with severe forms of schizophrenia commit suicide, usually in the younger age groups. Although there have been some specific examples of violent attacks upon strangers, in general people with schizophrenia do not pose a danger to others..

(vi) **Medication** is generally effective in controlling hallucinations, delusions and thought disorder. Depot injections of long-acting drugs at two - to four - weekly intervals are useful to ensure that medication has been taken. These have to be given regularly and are likely to be needed as long-term treatment. Relief of symptoms is achieved in at least 70% of people with such treatments. However people who are receiving medication and regular supervision on at least a weekly basis by a community psychiatric nurse or other medical professional are likely to be among the most severely affected with a significant level of care needs.

(vii) **Side-effects** of the antipsychotic drugs used may pose particular problems, especially those adverse drug effects on movement. Parkinsonian symptoms [see Chapter 15] may occur. Sedation or depressed mood, or restlessness may also be distressing.

19.5.3 Outcome

(i) Up to 20% of people with schizophrenia will require long term, highly dependent structured care, sometimes in a hostel with day and night staff.

(ii) About half of affected individuals can live relatively independent lives with the need for varying levels of support and care, but require continuing medication.

(iii) Around 30% make a complete recovery from a single episode of illness and are independent, usually working full time, and raising families. General indications of a good outlook are a rapid onset, a short duration of illness, evidence that the person may also be depressed, onset in middle age, and a previously good social and work record.

19.5.4 Care Needs

(i) In the past, the care of people with schizophrenia was largely hospital based. The emphasis now is on integration in the community whenever possible. This may include living in group homes or attending day centres.

(ii) Hostels or group homes vary in structure and support, from the high dependence that can provide 24 hour care to semi-independence of a supported flat with someone visiting daily or less often. Attendance at a day unit can improve personal functioning (for example, hygiene, conversation and friendships) as well as providing early detection of relapse.

(iii) Whilst it may appear that people are functioning relatively well in the community, this may be only because of the level of support being provided, and is not necessarily an indication of low care needs. Without that support some people might neglect to take care of their personal needs and omit to take medication. As a consequence without such support some could return to a severely disturbed mental state.

(iv) When the person's mental state is severely disturbed there may be risks of danger arising from forgetfulness due to poor concentration. There may also be a need for supervision to avoid danger both to the person and to others. A person with a severely disturbed mental state will usually require hospitalisation, at least initially.

(v) Risk of suicide must be considered in young people with severe forms of schizophrenia [see para 19.5.2(v)]. Here again hospitalisation is likely if there is a requirement for continuing supervision because of that risk, but the mere absence of hospital admissions should not be taken to indicate that the risk does not arise

19.5.5 Mobility Considerations

(i) People with schizophrenia will be physically able to walk unless another disability or illness limits walking ability.

(ii) In the early stages of schizophrenia there may be a need for guidance or supervision when the person walks outdoors. However this need is likely to be short lived. Similarly, the adverse effects of drugs (particularly those

referred to as psychotropic drugs) which may produce muscle rigidity and symptoms of Parkinsonism [see Chapter 15] which to a certain extent can limit walking ability, are unlikely to persist for more than a few weeks. Drug treatments are available which counteract these types of side-effect. In some people long-term side effects of the psychotropic medications can persist, although not to an extent likely to affect walking ability.

19.5.6 Duration of Needs

(i) See outcome at paragraph 19.5.3 above.

(ii) A rapid onset of schizophrenia in middle age, without a previous history of psychological problems, may indicate that the person will respond well to treatment and not have any long term care needs. However, a more gradual onset in a younger person may indicate that the condition and its associated disabilities is likely to persist for very many years and, indeed, in some throughout life.

(iii) The prescription of long-term medication, including the use of depot injections, may be an indication that the condition has been difficult to control and that the level of care needs in the individual person are likely to be long-standing. Similarly, a high level of professional support in the community (see paragraph 19.5.4 (ii)) is only likely to be given to those with significant ongoing disability.

19.5.7 Further Evidence

(i) In many cases, people with schizophrenia may not be able to express adequately their needs on the self-reporting claim form. A factual report from the consultant psychiatrist, the community psychiatric nurse, other mental health professional, or the general practitioner should be sought to establish the level of support and care needs required. In complex cases advice may also be sought from a Medical Services doctor to assist in posing questions which will focus on particular aspects of the person's management and care needs that require clarification.

19.6 Severe Depressive Disorder [Psychotic Depression; Manic Depressive Psychosis; Bipolar Affective Disorder]

19.6.1 Introduction:

(i) Depression is a word commonly used by people when describing feelings of unhappiness. However, depression becomes a recognisable illness when the degree of mood change is out of proportion to the circumstances and is unduly prolonged. It is also normal to feel elated at times of good fortune. Mania, however, is also a recognisable illness when the degree of elation

(ie. elevated mood) is highly abnormal and frequently accompanied by overactivity and self important ideas.

(ii) "Affect" means the same thing as mood. In those conditions where the main feature is an abnormality of mood, the term affective disorders is sometimes used.

(iii) Severe depressive disorder is sometimes called **psychotic** depression because like other psychoses it is a severe mental illness in which there can be delusions and/or hallucinations. In this type of severe depression there is most commonly no apparent cause for the profound state of misery. Because of this it is sometimes referred to as **endogenous depression**. In other words, the symptoms are caused by factors within the individual person and are unrelated to external stressors such as unsatisfactory life situations. However there are people with **endogenous depression** who, though severely depressed, do not show psychotic features like hallucinations, etc.

(iv) When psychotic depression occurs in people who also have bouts of mania with intense feelings of well being and grossly overactive behaviour, the mental illness is called **manic-depressive psychosis**. Because of these swings in mood the illness may also be called **bipolar affective disorder**.

(v) Another form of depression is usually associated with an obvious cause (eg. bereavement, redundancy, failed marriage etc) and this form is usually a much milder illness. It is referred to as mild depressive disorder or reactive **depression** or **neurotic depression** Usually this is a mild depressive disorder but in some people with reactive depression individual responses to major adverse life events can precipitate more severe forms of depressive illness. [See paragraphs 19.7.7]. Physical symptoms (eg poor appetite, weight loss, constipation, loss of sex drive) occur to a varying extent in mild depressive disorder, but are commonly much less severe than in people with severe depressive disorder, and care and mobility needs are not usually present.

(vi) **Post natal depression** is a disorder which affects women shortly after childbirth. In the great majority of cases this is a mild condition (commonly called "the baby blues") which resolves spontaneously within a few days. A few women, however, develop a severe psychotic depression which may last several weeks and require hospital treatment.

(vii) This section is not concerned with feelings of sadness or elation as normal experiences but with those mental illnesses in which the single most important feature is disturbance of mood. Sometimes, even in medical reports from general practitioners the term "depression" is used rather loosely to describe states of unhappiness rather than the recognisable mental disorder.

19.6.2 Clinical Features:

Severe Depressive Disorder:

(i) Each year around 100 per 100,000 men and at least three times as many women, develop severe depressive disorder. The mood is one of misery. It does not improve substantially in circumstances where ordinary feelings of sadness would be alleviated. However in some people with this illness the mood is usually worse in the morning and tends to improve somewhat later in the day. Pessimistic thoughts are also present. Feelings of hopelessness may occur with self-blame about minor matters. Slowness of thought may also be evident.

(ii) Lack of interest or enjoyment is common and leads to withdrawal from social activities. Reduced energy is characteristic with feelings of profound lethargy so that normal daily tasks are either not attempted or left unfinished.

(iii) Biological or physical symptoms are present. They include physical inertia, sleep disturbance, loss of appetite, loss of weight, constipation, and amenorrhoea in women of child-bearing age (absence of menstrual periods). Complaints about physical symptoms are common, sometimes with hypochondriasis (ie morbid anxiety about health). Suicidal thoughts may also occur.

(iv) In addition there may be delusions and hallucinations. These are usually centred around feelings of worthlessness

(v) Of all the severe mental illnesses, depression is the one most likely to respond to current medical treatment. The pattern of the depressive illness in the majority of cases is usually of recurrent episodes lasting several weeks or months interspersed with longer periods of normal mood. Some people experience only one episode and some are more or less continuously depressed for several years.

Mania

(vi) The central features are elation or irritability, increased activity and self-important ideas. The mood may be euphoric (intense feelings of well being) and may vary during the day. Overactivity is often persistent and can lead to physical exhaustion. The affected person is distractible starting many activities and leaving them unfinished. Sleep is often reduced; appetite is increased and in severe forms of the illness, sexual behaviour may be uninhibited. Women sometimes neglect precautions against pregnancy.

(vii) Expansive ideas of self-importance occur which at their extreme may be grandiose delusions. For example, the person may believe that he is a religious prophet or a world renowned expert on some matter. Persecution delusions may also be present. However the delusions are not long-lasting and usually disappear or change in content within days. Hallucinations also occur, usually taking the form of a voice telling the person that he has special powers, etc. Insight is impaired. The person seldom thinks he is in need of treatment.

(viii) In bipolar affective disorder or manic-depressive psychosis mania and depression may follow each other in a sequence of often rapid changes. Also included in this group are people with severe depressive disorder who may have had only one episode of mania. Moreover most people with mania eventually develop a depressive disorder. In any one year the incidence of bipolar affective disorders is 10-15 per 100,000 for men, and up to twice this rate for women.

19.6.3 Care Needs

(i) Suicide and attempted suicide are part of the pattern of some cases of severe depressive disorder. However fleeting thoughts of suicide are common in people with many mental health problems. In untreated severe depression, the only factor preventing suicide may be the associated apathy and physical inertia. The risk of suicide is therefore greatest in the early stages of treatment, when such symptoms begin to improve before there is any significant change in the overall mental state. Risk of self harm is also greater when moods swing from mania to depression or vice-versa. In these situations the person is likely to be hospitalised to guard against any risk. Only continuous supervision is likely to thwart serious suicide attempts in those at risk, and this is not practical in the home situation.

(ii) In those people with severe depressive disorder who show self-neglect there may be a need for care to maintain nutrition and cleanliness and to conduct essential business and communication. It must be remembered, however, that the majority of depressive episodes of this severity are of fairly short duration, counted in weeks rather than months. In very severe cases where the person remains motionless and mute hospitalisation is invariable.

(iii) In the great majority of people with severe depressive disorder the onset of the depressed mood is not so sudden that it demands continual supervision or watching-over at night. In people with mania who have grossly abnormal overactive and disturbed behaviour there may be a need for supervision and watching-over. Once recognised, however, treatment is instituted promptly, frequently in hospital, and in the very great majority within a few weeks there is a response to treatment.

(iv) When depression either accompanies or is a symptom of other co-existing disorders, such as alcoholism or substance abuse [See Chapter 22] or physical disability other care needs may be present.

19.6.4 Mobility Considerations

(i) Agoraphobia is a not uncommon feature of depression; it usually responds to antidepressant medication. Physical inertia and apathy may result in the carer needing to encourage the severely depressed person to get out and about. This, in itself, constitutes neither guidance nor supervision. The evidence will have to be scrutinized in the individual case to determine whether there is a need for guidance or supervision outdoors. It is unlikely however that features of this severity will last for more than a few weeks at any one time.

(ii) Apart from the rare occurrence of depressive stupor (motionless and mute) in very severely depressed people, neither the depressive disorder nor mania affects the ability to walk. Persons with depressive stupor will be hospitalised and respond to treatment within a period of weeks.

19.6.5 Duration of Needs

In the great majority of cases any evident care needs will only be for a limited period which is unlikely to exceed several months during any one episode.

19.6.6 Further Evidence

(i) In all cases of severe depressive illness or bipolar affective disorders it is highly probable that a consultant psychiatrist will have been involved in the management and treatment of the individual. Indeed the absence of any documented history of a psychiatric consultation should raise doubts about the nature and/or severity of the given diagnosis.

(ii) Hospital factual reports should be obtained. Other sources of information will be community psychiatric nurses, general practitioners and mental health social workers.

(iii) In those instances where it appears that the claim pack has been inadequately or inappropriately completed by someone described as having a mental illness of the types described here, it would be helpful if a report were obtained from an examining medical practitioner.

19.7 The Neuroses

19.7.1 Introduction

These mental illnesses are also referred to as psychoneuroses. The symptoms and disabilities associated with them are very often less severe than those encountered in the psychoses. Like the latter, however, they occur in people whose mental and intellectual development had been proceeding normally. They also differ very substantially from the psychoses in that the affected person neither loses touch with reality nor experiences disturbed thought processes. Anxiety is a symptom which they all have in common.

19.7.2 Anxiety

Anxiety is an unpleasant emotional state characterized by fearfulness and unwanted and distressing physical symptoms. It is a normal and appropriate response to stress but becomes a recognisable illness when it is disproportionate to the severity of the stress, continues after the stressor has gone, or occurs in the absence of any external stressful event. Neuroses with anxiety as the chief symptom are common: around 16% of the population are affected by some form of an anxiety illness at any one time.

19.7.3 Generalised Anxiety Disorder

(i) Anxiety disorders are not the same as the more fleeting stress reactions where anxiety occurs suddenly to stressful life events or follows some weeks later such events as loss of job, moving house, or divorce, etc. These are either acute stress reactions or adjustment reactions to stress which are generally self-limiting.

(ii) Generalised anxiety disorder affects 2-5% of the population but accounts for almost 30% of mental health problems in general practice. It is characterised by irrational worries, muscle tension, fearful feelings and physical symptoms such as rapid pulse or sweating. The disorder and its effects are mild in the very great majority of people who are prone to it. The symptoms are unpleasant but they are not likely to impair the person's ability to attend to bodily functions unaided nor are they likely to place the person or others at risk of substantial danger.

19.7.4 Panic Disorder

(i) Although panic may occur as part of different mental illnesses, panic disorder is the occurrence of unpredictable attacks of anxiety with pronounced increases in heart rate and forceful beating of the heart (ie palpitations) with sweating. Tremor may occur together with feelings of light headedness which may be due to overbreathing (hyperventilation). Common features are fears of dying and an urgent desire to flee.

(ii) Whilst subjectively most distressing for the person affected by the panic disorder its occurrence is unlikely to put the person or others at risk of substantial danger. The brevity and nature of the mental and physical disturbances it causes should not prevent a person attending to their bodily functions.

19.7.5 Phobic Anxiety Disorders

(i) Persons affected by these disorders recognise that their fears of particular situations or objects are excessive but are most difficult to control. Acute anxiety attacks, with or without panic disorder, occur on being confronted with the particular situation or object at the centre of their fears.

Agoraphobia

(ii) Agoraphobia tends to start between the ages of 15 and 35 and is twice as common in women as in men. Affected persons experience acute anxiety and, sometimes, panic when they are in, or anticipate being in, open spaces or in places where escape might be difficult or help might not be available. They have an intense desire to be somewhere else. Anxiety producing situations are avoided and just thinking about going into such situations may produce anxiety.

(iii) Although people affected in this way may well be distressed by being out alone, or at the thought of going out alone, this does not necessarily mean that they need supervision in order to take advantage of the faculty of walking out of doors. In each case it will be necessary to determine what function the other person provides and what would happen should that person not be there. It will be important to distinguish between whether the disabled person could not, or would prefer not to walk out of doors without the presence of another person".

(iv) Some people with agoraphobia feel better when accompanied by someone out of doors, and indeed may often be unable to face going out unless accompanied by another person. However, rarely would they be in danger should an attack occur when unaccompanied. There would be no need for guidance; though reassurance and support may be provided to some people to prevent panic attacks or to provide comfort and reassurance should they occur.

Social Phobia

(v) Social phobia is a persistent fear of performing in social situations, especially where strangers are present or where the person fears embarrassment. Their avoidance of these situations may interfere with their daily routine, work, or social life. These situations are predictable and the anxiety experienced is not likely to pose a risk of danger. Personal attention to bodily functions is unaffected.

Specific (Isolated) Phobias

(vi) This is an irrational fear of specific objects (ie spiders) or situations (ie enclosed spaces - claustrophobia). Some surveys suggest that up to 9% of the population will have a specific phobia of some kind.

(vii) The fear of being left alone in the house may bind a person to another, usually the spouse, by day and by night. If left alone they become anxious, distressed or may panic. They may not, however, be in substantial danger. A persistent agitated state may be a presenting symptom of an underlying depressive illness (agitated depression).

Post Traumatic Stress Disorder (PTSD)

(viii) Anxiety and other symptoms may briefly follow any traumatic event. Post traumatic stress disorder (PTSD) is a specific condition which may arise as a result of direct exposure to an extremely severe, life-threatening traumatic

event such as a major disaster or similar catastrophe. Severe physical assault may also result in PTSD.

(ix) PTSD needs to be distinguished from milder forms of stress reaction. Characteristic symptoms are vivid "flashbacks" in which the person relives the traumatic event; avoidance of situations which remind the person of the event; and personality changes such as irritability or blunting of the emotions. These, and symptoms of anxiety and/or depression, are particularly intense and prolonged. Symptoms must have been present for at least one month for a diagnosis of PTSD to be made, and they may last for up to two years; in some cases they will be lifelong. Confirmation of the diagnosis, and an opinion on prognosis, should be sought from the hospital or other specialist providing treatment.

(x) The effects of PTSD will depend on the features of anxiety and/or depression which are found in the individual person. Reference should thus be made to the relevant sections of this chapter.

19.7.6 Obsessive - Compulsive Disorder

(i) People with this disorder have obsessional thinking, compulsive behaviour and varying degrees of anxiety or depression.

(ii) Obsessional thoughts are words, ideas, and beliefs, recognised by the person as his own, which intrude in a compelling way into the person's mind and which he tries to exclude.

(iii) Obsessional rituals can include senseless behaviour such as washing the hands 20 or more times a day or having to check repeatedly that the gas has been turned off or a door has been locked, etc. The people are aware that these rituals are illogical but unless they perform them their feelings of anxiety can become unbearable.

(iv) Depending upon the type of obsessive thought or compulsive behaviour the life style of the person may be restructured to a varying extent. It is, however, unlikely that the manifestations of the disorder would place the person or others at risk of danger. The need for care from another in connection with bodily functions is most unlikely.

19.7.7 Mild Depressive Disorder [neurotic depression, reactive depression]

(i) The reader is advised to refer to the "Introduction" to the section on Severe Depressive Disorder [paragraph 19.6.1] for a description of depression. That section also distinguishes mild depressive disorder from severe [psychotic] depression.

(ii) In mild depressive disorder there are symptoms which can be broadly categorized as "neurotic" (ie: as a result of a neurosis rather than a psychosis) These include anxiety, phobias, obsessional symptoms. In addition to these symptoms, people with mild depressive disorders will also have a degree of low mood, lack of energy, and irritability. Biological

(physical) symptoms such as poor appetite and weight loss etc, may be found, but are usually much less severe than those which occur in people with major depressive disorder. Delusions and hallucinations do not occur.

(iii) These forms of mild depression are often brief, starting at a time of personal misfortune and subsiding when fortunes have changed or new adjustment has been made to the prevailing situation. Sometimes, however, the symptoms may persist for months or years.

(iv) The magnitude of change in mood, its duration, and the effects of associated neurotic symptoms rarely result in significant or prolonged care needs. People with mild depressive disorder should not require guidance or supervision when walking out of doors. If anxiety is evident as the principal feature of an individual person's mild depression then reference should be made to the section of this chapter on Anxiety [paragraph 19.7.3].

19.7.8 Care Needs and Mobility Considerations- The Neuroses

(i) As with physical illnesses the care and mobility needs can vary considerably between people who have the different types of neurosis, and can vary just as much between people who have the same type of neurosis (ie. anxiety, panic disorder, mild depressive disorder, etc). Each case must be considered on the basis of the manifestation of the mental health problem and the needs that may bring in each individual.

(ii) Anxiety (with or without panic episodes) is likely to be the principal feature among people who are affected by the different neuroses. Even in mild depressive disorder anxiety is a prominent symptom. The mental symptoms, and sometimes physical accompaniments, of anxiety can be highly distressing but they are unlikely to require attention from another in connection with bodily functions. Moreover the effects of anxiety or panic episodes are unlikely to place the person or others at risk of danger.

(iii) Even in those people with agoraphobia or social phobias who demand to be accompanied, these events will be predictable and intermittent and not amount to a need for supervision. Although reassurance and comfort may be welcomed by the affected person when walking outdoors, there would be no need for guidance by virtue of the heightened anxiety state or panic episode should these occur. Furthermore, the affected person's mental and behavioural responses to the onset of acute anxiety and/or panic when outdoors, whether or not accompanied, are not likely to lead to danger to the person or others. Claims that the panic episodes could result in the person becoming disorientated and not knowing how to get to a particular destination, or that there is a risk of an impulsive action (eg: running out under a bus) are most unlikely consequences of even severe panic episodes.

(iv) In people with mild depressive disorder the degree of mood change, its variability and duration, and the effects of accompanying anxiety, rarely result in significant care needs.

19.7.9 Further Evidence

(i) Information obtained from someone who is caring for, and familiar with the disabled person is likely to provide a fuller picture of the needs which may arise in those people with mental health problems falling into the group of neurotic illnesses.

(ii) Few of those people affected by one of the anxiety illnesses or mild depressive disorder will have been under the care of a consultant psychiatrist. The majority of these people with the milder forms of mental health problems are managed by the general practitioner. A factual report from the general practitioner supplemented, if necessary, by a report from the community psychiatric nurse will be helpful.

(iii) With regard to the risk of danger a relative's fears may not always provide the necessary evidence of a need for supervision - whether this be when the person is walking outdoors or in the home environment. Assumptions about care needs cannot be based solely on the common manifestations of a particular diagnosis.

(iv) In those cases where it appears that the claim pack has been inadequately or inappropriately completed by or on behalf of someone described as having a mental illness or mental health problems, it would be helpful if a report were obtained from an examining medical practitioner.

19.8 Personality Disorders

19.8.1 Introduction

(i) Personality refers to those persisting characteristics of a person that are demonstrated by the ways in which the person behaves or reacts in a wide variety of circumstances. These characteristics or traits can be used to describe, in broad terms, the type of personality. For example, a person who is basically friendly, outgoing and likes mixing with other people is said to have a "social trait" to the personality. Some persons are by nature very cautious and careful ("obsessional trait") or very easily provoked to aggression ("aggressive trait"), or falling in very easily with the wishes of others ("dependent trait"). People's personalities are a mix of these various traits but one is usually more evident than the others.

(ii) In a few people the main (dominant) personality trait is so overbearing and predominant that it causes major difficulties to the person and for other people. Such a person is then said to have a **personality disorder.**

19.8.2 General Features

(i) Personality disorders can cause considerable problems to the persons who have them, to the persons' families and to people with whom they come in contact.

(ii) The behaviour of people with personality disorders will depend on the particular type of dominant personality trait, and can vary from being unable to take any responsibility for themselves to being thoroughly impulsive and irresponsible in their actions. Very rarely there are severe personality disorders which are difficult to differentiate from psychiatric illness.

(iii) People with a predominantly **dependent personality disorder** are weak-willed, passive and readily compliant with the wishes of others. They may avoid responsibilities and lack self reliance, drive and enthusiasm. Some react by persuading other people continually to help and assist them because of what they describe as their own helplessness. If married or in long-term relationships, such people may have the support of more self-reliant spouses or partners who may care for their every need. Sometimes this support is provided by several members of the family or by a son or daughter who may have committed their life to supporting and caring for the perceived helplessness and demands of the highly dependent and demanding parent.

(iv) Another type of personality disorder which may make demands on other people for support and care is the **antisocial (dissocial) personality disorder**. This type of personality disorder is sometimes referred to as **psychopathic**. However this term is no longer in routine use because it has certain connotations which are pejorative, deprecatory or are coloured by the loose use of the term in the media and drama to describe criminal or murderous individuals. At one extreme the person with an antisocial personality disorder can show lack of guilt, highly impulsive behaviour and failure to learn from life experiences. When these are accompanied by low tolerance of other people's needs and violence or aggression they may, indeed, lead to repeated offences against the law.

(v) Alcohol abuse or drug dependency may be a feature of some people with serious personality disorders. In such cases reference should be made to Chapter 22.

19.8.3 Care Needs

(i) People with a personality disorder (or a member of their family) may claim that there are care needs because of the effects of the personality disorder. In those with a dependent personality disorder attention to bodily functions may be claimed. However the person with such a

personality disorder will usually be capable of attending to their bodily functions in the absence of any other co-existing disabilities. However, people with dependent personality disorder may experience greater difficulties in coping with the needs which may arise from co-existing disabilities.

(ii) Impulsive or irresponsible behaviour by some people with antisocial personality disorders may be advanced as a reason for supervision or watching-over. It would be rare for someone with such an antisocial personality disorder which produces behaviour that poses danger to the person or others to be permitted to remain in the community.

(iii) **Therapeutic community methods** are sometimes used, in which people with the more severe forms of personality disorder reside in, or attend, a therapeutic community for several months where they can talk about their problems in relationships and try to help other members of the group to identify and resolve their own problems. This form of therapy as well as group or individual counselling may be of benefit. However, treatment in such a therapeutic community does not imply the presence of any significant care needs.

19.8.4 Mobility Considerations

(i) Supervision when walking out of doors is most unlikely to be required by someone living in the community who has a personality disorder. [See also paragraph 19.7.8 above].

19.8.5 Further Evidence

(i) The borderline between the limits of a normal personality and personality disorder is hard to define. Moreover, the effects of personality disorders themselves are highly variable. It is very likely that someone with a personality disorder whose effects are so disruptive or disordered that they are claimed to give rise to care needs, will have been assessed by a consultant psychiatrist and will be known to the local psychiatric and social community services.

(ii) Confirmation of the diagnosis and an assessment of its principal features is essential. Information should thus be sought from a hospital doctor (usually, consultant psychiatrist) who has been involved in the case. It may also be helpful to seek information from the general practitioner or mental health care worker.

19.9 Dissociative (and Conversion) Disorders; Hysteria, and Somatoform Disorders)

19.9.1 Introduction

(i) **In dissociative and conversion disorders** the predominant symptoms are physical . The term conversion disorder implies that in the affected person anxiety has been replaced by (or "converted into") physical symptoms. It

is assumed that the physical symptoms serve a function in that they enable the affected individual to avoid situations with which they cannot cope. These disorders are also forms of neurosis; but in view of their importance and the critically important need to differentiate them from malingering where an apparent disability is out of proportion to the physical condition,this separate section is devoted to them and related disorders.

(ii) An alternative name for these disorders is **hysteria**. Although this term is still in use, many psychiatrists avoid it because colloquially it is used to describe exaggerated and extravagant displays of emotion. This is not the meaning of hysteria when used in the clinical context.

(iii) **Somatoform** or **Somatization disorder** is a type of conversion disorder. It is used to denote a chronic condition characterised by a history of numerous, variable and recurrent physical complaints that may begin in early life and persist for many years. These physical symptoms are not accounted for by physical disease. In one form of the disorder there are complaints of chronic pain which cannot be explained by any primary physical or mental disorder.

(iv) A dissociative (or conversion) symptom suggests physical illness but occurs in the absence of relevant physical findings and any evidence of physical disease. The symptom arises from unconscious psychological mechanisms.

(v) A definite diagnosis of a dissociative (or conversion) disorder made by a consultant psychiatrist implies that attempts have already been made to ensure that as far as possible underlying relevant physical disease has been excluded.

(vi) In reaching that diagnosis the psychiatrist also has to be satisfied that the symptoms arise unconsciously rather than consciously and deliberately. The deliberate feigning of symptoms is known as **malingering** and this is dealt with separately at paragraph 19.11.

19.9.2 Clinical Features

(i) Although dissociative and conversion symptoms are produced unconsciously they are shaped, in the individual person, by that person's knowledge and understanding of illness. Usually there are **discrepancies between the signs (clinical findings) and symptoms (what the person complains of)** and those of an identifiable specific disease. For example, a report of a medical examination may reveal a pattern of loss of sensation in a part of the body that does not correspond to the way in which that part of the body is supplied by nerves which carry the feeling of sensation to touch, etc.

(ii) **Secondary gain** is a term which is sometimes used in medical reports on people with dissociative disorders. This means that the symptom confers some immediate advantage on the affected individual. An example of secondary gain is the advantage that conversion disorder which manifests as, say, paralysis of the legs, might bring by relieving the person from the stressful care of a relative with severe disabilities.

(iii) The manifestations of these dissociative disorders are many, ranging from muscle paralysis and unusual patterns of walking (disorders of gait) through convulsions to apparent blindness or deafness and the complaint of chronic pain

(iv) **Psychogenic** is another word which may be used to describe a symptom of a dissociative or conversion disorder.

(v) People with **somatization disorder** have multiple complaints over long periods. They may consult many doctors throughout life. Associated depressive and anxiety symptoms are common.

(vi) **Hypochondriacal disorder i**s a persistent preoccupation with the possibility of having a serious illness. Frequently, people with this disorder attach major significance to even minor symptoms

(vii) Adopting the "**sick role**" or the "**patient role**" also appears sometimes in medical reports. They are not very helpful because they may indicate that the person has a dissociative (conversion) disorder or that the role has been adopted as a matter of choice. "Illness behaviour" is a common response to a situation which is perceived as an intolerable predicament. The advice of a Medical Services doctor should help to clarify the situation.

(viii) **Functional Overlay** is another term which may be found in medical reports. This is usually interpreted as unconscious exaggeration or elaboration of symptoms for which there is an organic basis. However it may be used by some doctors to indicate an element of conscious exaggeration too. When it appears in reports Adjudication Officers are advised to seek advice from a Medical Services doctor for interpretation of its meaning in the particular context.

19.9.3 Care Needs and Mobility Considerations

(i) Most people with dissociative and conversion disorders of recent onset recover quickly (ie within a matter of several months). Those cases that persist for longer than a year are likely to continue for many more years.

(ii) People with dissociative (or conversion) disorders including those with somatization are neither consciously nor deliberately feigning their symptoms. Thus care needs and mobility requirements must be assessed on the same basis as if the manifest disabilities were due to a recognised specific physical disease

19.9.4 Further Evidence

(i) It is absolutely essential that a reported diagnosis of dissociative or conversion disorder, hysteria or somatization is confirmed by obtaining a factual report from a hospital attended by the person or from a doctor or community psychiatric nurse in the psychiatric services involved with the person.

(ii) Sometimes a report from an examining medical practitioner or a factual report from the GP will mention a diagnosis of somatization, hysteria or dissociative/conversion disorder, or use the term psychogenic. In these circumstances, and in the absence of any documented confirmation of the diagnosis by a consultant psychiatrist, advice should be sought from a Medical Services doctor on the most appropriate source of further evidence to confirm or refute the diagnosis and to establish the nature and extent of the resultant disabilities.

19.10 Factitious Disorder

19.10.1 Factitious disorder refers to the intentional physical self injury or the production of physical signs of disease or the feigning of physical or psychological symptoms, with the apparent aim of being diagnosed as ill.

19.10.2 This disorder is not the same as malingering [see paragraph 19.11] in that its primary aim is not to bring external rewards such as avoidance of duties or fraudulent financial gain, but to obtain medical attention. People with factitious disorder often have very disturbed personalities.

19.10.3 Some common features seen in people with factitious disorder are skin lesions which are produced by self-injury **(this is sometimes called dermatitis artefacta)** or their presenting with an apparent high body temperature (pyrexia) produced by various means, such as rubbing the bulb of a clinical thermometer to produce frictional heat or dipping the thermometer in a hot drink when unobserved. Some people with this disorder may deliberately aggravate an existing physical disorder, for example by preventing the healing of the ulcers which sometimes occur due to varicose veins in the legs.

19.10.4 Munchausen syndrome is a rare but extreme form of the disorder in which the affected individual will give a plausible account of an illness with feigned symptoms and signs. These may include psychiatric symptoms. These people often present themselves at a series of different hospitals using different names.

19.10.5 Munchausen syndrome by proxy is used to describe a condition in which an adult with a personality disorder, in charge of a child, gives a false account of symptoms in the child and may fake physical signs of illness in the child.

19.10.6 Care Needs and Mobility Considerations

Although there is no evidence that financial gain is involved in people with factitious disorder, and though some affected people may also have abnormal personalities [see paragraph 19.8], there is nevertheless a conscious and deliberate intention to simulate illness. There is no specific treatment and though supportive counselling may be offered, many people affected by this disorder refuse treatment. Counselling cannot be considered as attention to bodily functions since it focuses on ways in which the affected person may come to terms with and cope with their own difficulties. Care needs and mobility requirements should not arise in people with factitious disorders in the absence of co-existing illnesses and disabilities which are not the product of conscious intentions to deceive.

19.10.7 Further Evidence

By its very nature and the conclusions which necessarily follow it, a diagnosis of factitious disorder must be confirmed by seeking a comprehensive report from a consultant psychiatrist. In all cases where this disorder is mentioned advice should be sought from a Medical Services doctor for assistance in framing questions to put to the psychiatrist and in interpreting the subsequent report.

19.11 Malingering

19.11.1 Malingering is the **fraudulent** imitation or exaggeration of symptoms with the intention of gaining financial or other rewards or material benefits. It is this obvious external gain that distinguishes malingering from factitious disorder [see paragraph 19.10]. Malingering is not common.

19.11.2 **Overstatement of degree of disability and needs** should not be classed as malingering without there first having been established that apparent exaggeration of care needs and mobility requirements is not due to a misunderstanding of the questions listed in the claim packs or, indeed, the eligibility requirements for an award of DLA or AA. [See also Chapter 2.3 and 2.4]

19.11.3 Care Needs and Mobility Considerations

Obviously, any portrayal of care/mobility needs by someone who is malingering is justifiably dismissed.

19.11.4 Further Evidence

The seriousness of an allegation of malingering is such that it must not be accepted without documented authoritative confirmation. Since the procedures which may be followed upon the confirmation of malingering

may well have grave consequences for the malingerer, it is essential that advice is sought from a Medical Services doctor and senior BA management for the subsequent handling of the matter.

20. LEARNING DISABILITIES

20.1 Contents: **Paragraph**

20.2 Introduction

20.2.1 Here there is a failure of normal mental development. Mental subnormality was formerly called mental deficiency and is also referred to as mental retardation or mental handicap. However, the preferred term is learning disabilities.

20.3 Intelligence Quotient

20.3.1 Intelligence quotient [IQ] or mental age assessment was not designed for the purpose of assessing the needs of a person with learning disabilities and can be very misleading in this context. Persons with the same intelligence quotient or mental age may have very different attendance needs. The fact that a man of 30 years has a mental age of 5 years does not indicate that he has the same needs as a normal child of 5 years. Among specialists in the field of mental impairment/learning disabilities there are generally accepted dividing lines between moderate and severe impairment of intelligence and the level of disability which results. It is necessary to distinguish between the two because their likely care and mobility needs will differ.

20.4 Moderate Learning Disabilities in Adults

20.4.1 Care Needs

(i) The needs of people with moderate degrees of learning disabilities may not be clear cut. For example, three or four people with learning disabilities may be placed in a house together where they cope with the daily round without continual supervision. A social worker calls once or twice a week to check on them. Although they may not be capable of completely independent living, they may not necessarily require supervision to avoid substantial danger or frequent attention in relation to their bodily functions. A person with learning disabilities living at home may appear at first sight to have achieved a degree of independence in that he goes out alone. However, it may be that he goes only to a local shop where he is known.

Considerable training may have been required to enable him to do this; he may be unable to cope with any deviation from this routine. When a carefully structured and limited environment has been created in which a person with learning disabilities can operate with an apparent degree of independence, but cannot cope with any deviation from the routine, he is in effect requiring continual supervision even though he may be out of sight of the carer for short periods of time.

(ii) A person with learning disabilities who has clearly established attendance needs, whether for supervision or attention to bodily functions by day, may not have the same needs at night. Such persons requiring attention or supervision by day may sleep peacefully throughout the night. Care and mobility needs may vary considerably between people with learning disabilities. Some may have such low levels of motivation that they would neglect to attend to bodily functions without prompting. Others may need supervision to avoid their being exploited by others.

20.4.2 Mobility Considerations

There may well be coexisting physical disabilities which make it difficult for the person to walk and get around. A person with moderate learning disabilities will not usually require guidance or supervision when out of doors. Each case will have to be considered individually in order to determine mobility requirements.

20.4.3 Further Evidence:

If required, further evidence may be obtained from a social worker or another professionally qualified person who is familiar with the person and their needs, to establish the degree of independence, the existence of other disabilities and whether there is a need for supervision/watching over.

20.5 Severe Learning Disabilities

20.5.1 Most people with very severe learning disabilities have been disabled from birth: either their brains did not develop properly, and will never do so, or they suffered brain damage at birth. Others have suffered brain damage later on as the result of an injury or accident.

20.5.2 Care Needs

(i) People in this group usually need a very great deal of care: they are most unlikely to learn more than the most basic skills such as feeding, dressing, going to the toilet. Many will not reach even this level. They are likely to need help with most of, if not all, their bodily functions and in most cases they are unaware of danger, indoors and out. A large proportion have physical disabilities which exacerbate the need for care.

(ii) Their needs for attention at night will vary from person to person: some sleep peacefully through the night; others do not and may need as much help, or be as likely to expose themselves to danger, as during the day.

20.5.3 Mobility Considerations and Behavioural Problems

People with severe learning disabilities may well need guidance and supervision when walking out of doors. Within this group of people there is a small number (thought to be between 10,000 and 12,000) who also have severe behavioural problems. Severe behavioural problems means extremely disruptive behaviour which may take many forms. Examples of this type of behaviour are uncontrolled temper tantrums, during which the person may hurt himself or others, or may sit down and refuse to move from a certain spot. In all such cases the behaviour is unpredictable, so that it is not possible to avoid situations that provoke it, nor to relax vigilance. People in this category who physically are able to walk would need a great deal of assistance and physical restraint.

20.5.4 Further Evidence

Expert advice will be needed about the degree of mental impairment. This is a complex specialist area, and not all health care professionals will have the necessary qualifications and expertise to provide it. A Medical Services doctor will be available to arrange for evidence to be obtained from a suitable source, normally a specialist in mental impairment familiar with the individual case.

21. DEMENTIA

21.1 Contents

21.2. Introduction

21.2.1 Dementia is an acquired, progressive impairment of overall mental function affecting memory, cognition (understanding) and personality without any clouding of consciousness. Though it can affect people at any age, it occurs mainly in the older age groups. About 5% of people over 65 years suffer from dementia and about 20% of those over 80. There are twice as many women with dementia as there are men.

21.3 Causes of Dementia

21.3.1 The principal cause of dementia is the degenerative condition of the brain known as **Alzheimer's disease**. Formerly, when it affected people under 65 years it was called pre-senile dementia and in those over 65, senile dementia. These terms are now less in use. The second most common cause is vascular disease of the brain which goes under the term **multi-infarct dementia**, often referred to in the past as arteriosclerotic dementia.

21.3.2 People suffering from conditions such as Huntington's disease or cerebellar ataxia frequently develop dementia as part of the illness. Less commonly it is associated with other conditions such as AIDS, Parkinson's disease and multiple sclerosis.

21.3.3 Whatever the underlying cause, the outcome of dementia is the same. Therefore, the same considerations apply to the determination of needs in any particular type of dementia irrespective of its cause.

21.4 General

21.4.1 Dementia causes impairment of memory, especially of recent short-term memory. A person may not remember where she has just put something or what she is about to do, yet retain memory of events long past. Recent memory impairment results in difficulty with shopping and even with simple tasks such as making a cup of tea. Frequently, the person will ask the same question repeatedly. This repetitive questioning can be very wearing for the carer. More severe memory loss leads to failure to change clothing and to neglect of personal hygiene.

21.4.2 The person may lose the ability to orientate in time and space, being unsure of the day or date, where she is, or who people around her are. This can contribute to wandering or aggressive behaviour.

21.4.3 Cognitive function, that is the ability to understand, is affected and there is a reduced ability to acquire new information. This often becomes apparent when the place of residence is changed, the person being unable to cope with the new environment. There is loss of understanding of what is read or heard and so the person has little knowledge of current affairs. The ability to calculate is affected so she cannot cope with money.

21.4.4 Judgement is also affected, leading to exposure to danger out of doors with traffic and indoors with fires and gas and electrical appliances. There may be inability to handle personal affairs. Personality is involved causing the person to behave differently from her customary pattern. She may become restless or aggressive and this behaviour can be very difficult to control.

21.4.5 Verbal communication often is affected, either because the person cannot put her thoughts together in a meaningful way, or because she can no longer coordinate the muscles of the face and throat in order to produce intelligible speech.

21.5 Care Needs

21.5.1 The first need of a dementing person is for supervision because of the loss of short-term memory. She may be unsafe cooking, not because she is unaware of the dangers involved, but because she forgets them. For example, she may forget that the gas is turned on but not lit. If reminded about it she will immediately appreciate the potential danger involved.

21.5.2 As the condition develops the person may need help at the beginning and end of the day with dressing and washing. The progressive decline in ability to care for herself will reach a point at which the person is in significant danger from accident or neglect. At this point she is no longer aware of dangers.

21.5.3 In the later stages of the disease there is a significant deterioration in physical ability as well as mental. Supervision alone will not then suffice; there is an increasing need for attention in connection with bodily functions.

21.5.4 The fact that a person with dementia requires supervision through the day does not mean that watching over is also required at night. Many demented people sleep undisturbed throughout the night. Even if the person does waken, she will often remain quietly in his bedroom in no danger. Others will wander and be at risk, particularly if they have other problems that put them in danger of falling. These people will need watching over.

21.5.5 Incontinence, commonly of urine, less commonly of faeces complicates many cases of dementia in time. It is often concealed by the person and by their carer because of embarrassment. This may add considerably to care needs.

21.6 Mobility Considerations

21.6.1 A dementing person may be unable to get about out of doors because of loss of short-term memory: She may need guidance because she cannot remember where she is going.

21.6.2 Physical deterioration in the late stages of the disease may also have a significant effect on the person's walking ability, and may in fact be so severe that the person becomes totally chair-or bed-bound.

21.7 Duration of Need

21.7.1 Dementia is a progressive condition and the needs of the affected person are likely to increase throughout the remainder of her life.

21.7.2 Damage to the brain such as a head injury or encephalitis (inflammation of the brain) may produce the clinical picture of dementia except that it may not be progressive. The disability resulting from this is the same as for dementia due to other causes. There is, however, some room for improvement over a period of a year or so. If after this period there has been no improvement the disability is then likely to be permanent.

21.8 Further Evidence

21.8.1 In moderate or severe cases of dementia the situation is usually readily apparent and the care and mobility needs are easily determined. However, general statements about risks to the demented population as a whole are not helpful. Of much greater importance is any specific evidence on care and mobility needs related to the individual person.

21.8.2 In less severe cases the presence of dementia may be overlooked, a person's unusual behaviour being attributed to other causes. The sufferer herself, lacking insight into her condition, may deny that she is unable to do things and give a false and over optimistic picture of her capabilities. In all cases in which dementia is suspected, evidence from the person caring for the disabled person is very helpful in getting a full and accurate picture of the overall disability. If there is no-one caring for the person then a report from

a GP may help. Alternative sources of information are the local authority social services or hospital geriatric department.

21.9 The Effects of Age

21.9.1 Because dementia mainly affects older people, physical disabilities are frequently present as well. The person may be less able to cope with these because of her mental state. The total needs because of the combination of physical and mental disability should be taken into account [see Chapter 3].

22. ALCOHOL AND DRUGS; ABUSE AND DEPENDENCY

22.1 Contents

22.2 Introduction

22.2.1 Alcohol abuse and dependency have become a major problem in contemporary society. As well as the adverse effects of alcohol per se, excessive drinking can increase the risk of developing a wide range of physical disorders. Abuse and dependency on a wide range of other drugs (both illegal and prescribed) and substances is becoming an increasing problem. Nevertheless, the circumstances under which alcohol and drug abuse lead to significant care and mobility needs are probably quite rare.

22.3 Alcohol Abuse

22.3.1 Alcohol Consumption and Dependency

It is estimated that large numbers of people drink alcohol at a level which puts them at risk of developing physical complications. A small number, however, develop a state of alcohol dependency. This is characterised by the person having to drink more and more to achieve the same effect, developing withdrawal symptoms when they stop taking alcohol, and a psychological craving which means they have great difficulty stopping or controlling the amount they drink despite being aware of the damage it is causing. Affected people will spend a great deal of time trying to ensure that their supply of alcohol is maintained and will become devious in trying to hide the amount they are actually drinking, Alcohol dependency (sometimes known as alcoholism) can be associated with a range of psychological and social problems, but should not be expected to give rise to significant care and mobility needs in the absence of any of the complications described below.

22.3.2 Alcohol Withdrawal Symptoms

These can vary in severity from a state of mild shakiness to Delirium Tremens which is characterised by severe shakes, sweating, high temperature and frightening visual hallucinations. Withdrawal symptoms last usually for a few days and should not lead to long-term help from another person.

22.3.3 Complications of Long Term Alcohol Abuse

Excessive consumption over a prolonged period can lead to a number of physical and psychiatric complications. These include cirrhosis of the liver, peripheral neuropathy, heart failure, Korsakov's psychosis, hallucinosis and dementia. The effects of these conditions may give rise to a need for attention or supervision which will be the same as those arising from the disabling effects of similar conditions not caused by alcohol abuse.

22.3.4 Repeated Drunkenness

In some people it may be claimed that attention or supervision needs arise from the behaviour problems during episodes of repeated drunkenness. In a few people these periods may be associated with prolonged memory blanks. During these periods people may indeed get into fights, into trouble with the police and may be at increased risk of accidents of various sorts. People with alcohol dependency have great difficulty in controlling their alcohol intake and such behaviour cannot be prevented by any reasonable supervision, although intermittent intervention by another person at specific times may reduce the risk at those times.

22.3.5 Alcohol and Self Neglect

Some people with alcohol dependency may fail to eat properly and develop protein and vitamin B deficiency. They may also fail to attend to personal hygiene and become incontinent of urine and faeces. When such a state of neglect becomes severe enough to require attention from another person, it is usually for a limited period; such help should not be long-term once drinking has stopped.

22.3.6 Treatment of Alcohol Dependency

The treatment of alcohol dependency can be difficult and many people relapse. Some people require a prolonged period of rehabilitation. During this the person may require considerable support from others, but this should not amount to a need for attention or supervision.

22.4 Drug and Other Substance Abuse

22.4.1 The abuse of a wide range of other drugs and substances is common,

although the overall problem is small compared to that arising from alcohol abuse. The drugs involved may either be available on prescription, or obtained illegally. The following are the groups of the most commonly abused drugs or substances:-

- Opioids (including heroin, morphine, methadone and codeine)
- Anxiolytic and hypnotic drugs (ie tranquillisers and sleeping tablets including diazepam, temazepam and related drugs).
- Stimulants (including amphetamines, ecstasy and cocaine)
- Cannabis
- Organic solvents (glues, gases and aerosols)

22.4.2 All drugs are taken for their acute intoxicating effects. The precise nature of these will vary according to the mode of action of the drug concerned. As with alcohol, these should not lead to any care needs.

22.4.3 Prolonged use of most drugs can lead to a state of dependency when withdrawal symptoms will occur on stopping. These vary according to the type of drug concerned. With opioids they can be severe and include nausea, vomiting, restlessness, diarrhoea, anxiety, sleeplessness, runny nose and eyes and joint pains. The person may need to be admitted to hospital, but symptoms should resolve in 10-14 days and perhaps rather longer with methadone. Withdrawal symptoms from diazepam (Valium) and related drugs can be more prolonged, but can usually be managed by gradually decreasing the dose over a period of time and a need for attention or supervision should not arise.

22.4.4 Drug dependency can lead to a range of psychological and social problems. These may be more complex than with alcohol because of the illicit nature of the drug concerned whereby the person may resort to criminality in order to maintain his addiction. However these should not lead to a need for attention or supervision. People can fall into a state of self neglect and similar considerations apply to assessing care needs as in paragraph 22.3.5.

22.4.5 Physical and psychological complications can occur as a result of taking many drugs. Most notably, hepatitis B & C and AIDS may result from using contaminated needles for injection. In addition, a psychotic illness [See Chapter 19] can result from the prolonged use of stimulants such as amphetamines. As with alcohol, any care and mobility needs which arise will be the same as those as when similar conditions arise from non-drug related causes.

22.5 Further Evidence

22.5.1 People with drug and alcohol dependency may be under the care of a consultant psychiatrist, or may be attending a Drug Dependency Unit or alcohol treatment centre. Alternatively the person may be under the care of

a community drug or alcohol team. A variety of professionals including counsellors and community psychiatric nurses may be involved. Where significant care and mobility needs are claimed, a factual report from one of these sources (depending on the individual circumstances) may help to clarify the situation.

23. EATING DISORDERS

23.1 Contents

23.2 Introduction

23.2.1 These are a group of disorders occurring most commonly in late adolescence and early adult life. Most affected individuals are female. This is a time of life when young people can become concerned with their appearance and dieting can be a part of this. In most individuals this does not produce serious problems and they are able to stop dieting without difficulty. In some however, this concern with appearance can become a preoccupation and one of the eating disorders may result. Affected individuals often have a low self-esteem.

23.3 Anorexia Nervosa

23.3.1 The main features of anorexia nervosa are low body weight and an intense wish to be thin. Affected women stop having periods (amenorrhea). At the onset, the person may be slightly overweight but on dieting become relentlessly preoccupied with achieving an abnormally low weight. About half of affected people indulge in binge eating (bulimia) - bouts of uncontrollable eating followed by self induced vomiting. Some people also take laxatives to further increase the weight loss. Vomiting and laxative abuse can affect the body chemistry which can occasionally lead to epilepsy and rarely death from a disturbance in heart rhythm. In severely affected cases there is also a risk to life from starvation or suicide. Associated depression is common.

23.3.2 Nearly 95% of affected individuals are female, the condition typically starting in adolescence and rarely after the age of 30. Some 1-2% of female college students are affected. About one fifth make a full recovery, in three fifths there is a fluctuating course, whilst the remaining one fifth become seriously ill.

23.4 Bulimia Nervosa

23.4.1 The term bulimia refers to episodes of uncontrolled and excessive eating (binge eating) followed by self-induced vomiting. Bulimia can form part of the picture of anorexia nervosa, but can also exist on its own and is then known as bulimia nervosa. Unlike in anorexia nervosa, the weight is normal and when it occurs in females, the periods are not normally affected. Weight gain is prevented through self induced vomiting, taking laxatives and by taking excessive exercise. Affected people tend to recognise that they have a problem, often feel depressed and frequently seek psychiatric help.

23.5 Care Needs and Mobility Considerations

23.5.1 Most people with anorexia nervosa are physically capable of feeding themselves, but they may need prompting to do so. If the person's weight loss becomes extreme and they become severely ill, they require intensive attention to feeding and to maintaining normal body chemistry. Such people will usually be admitted to hospital. It may be claimed that a person needs the supervision of another person to prevent excessive vomiting. People with this disorder generally become extremely devious and in practice there is no way of preventing this other than by the 24 hour presence of another, which is not a practical proposition on an ongoing basis. People with anorexia nervosa, unless extremely emaciated, would not normally be expected to have any mobility needs.

23.5.2 In bulimia nervosa, because severe weight loss is absent, care needs are significantly less than those for anorexia nervosa.

23.6 Further Evidence

23.6.1 People with eating disorders are usually under the care of a consultant psychiatrist. A factual report from this source may help to clarify the level of need in cases where this is in doubt.

24. RENAL DIALYSIS

24.1 Contents

24.2 Introduction

24.2.1 Two groups of people suffering from renal failure and undergoing dialysis treatment two or more times a week are "deemed" to satisfy one or more of the medical criteria for the middle rate care component of Disability Living Allowance or the lower rate of Attendance Allowance. These are:

(i) Those undergoing a type of dialysis which normally requires the attendance or supervision of another person during the period of dialysis.

(ii) Those who because of the particular circumstances of their case in fact require another person, during the period of dialysis, to attend in connection with their bodily functions or to supervise them in order to avoid substantial danger.

These people may have other care and mobility needs which also have to be taken into account when the overall needs are assessed.

24.3 General

24.3.1 Chronic renal failure may result from any progressive destructive condition affecting both kidneys. It can develop at any age. It usually develops slowly over months or years although it may develop very rapidly. It is only in the final stages when there is no useful renal function remaining that dialysis is used as treatment.

24.3.2 The condition causing the renal failure is not in itself important unless it has other effects that give rise to care and mobility needs. For example, diabetes mellitus [Chapter 17] and systemic lupus erythematosus (SLE) [Chapter 28] can cause chronic renal failure. However, the effects of renal failure are the same whatever the cause.

24.4 Types of Dialysis

24.4.1 The purpose of dialysis is to remove from the body those toxic substances that are normally removed by the kidneys. There are two basic types, haemodialysis and peritoneal dialysis. There are three types of peritoneal dialysis, intermittent peritoneal dialysis (IPD), continuous ambulatory peritoneal dialysis (CAPD) and continuous cycle peritoneal dialysis (CCPD). CCPD is also known as peritoneal rapid overnight dialysis (PROD).

24.4.2 In general, those undergoing haemodialysis and intermittent peritoneal dialysis will need attention or supervision during the period of dialysis although a small number of people do manage unaided. CAPD and CCPD are designed in such a way that an adult who is otherwise physically and mentally fit does not need assistance with the procedure and does not need supervision during the period of dialysis. For many adults, however, age or the presence of other disabilities mean that they do in fact need attention or supervision during the procedures. Children will also need attention and/or supervision during the periods of dialysis.

24.5 Haemodialysis

24.5.1 Modern management of renal failure would not be possible without the use of the artificial kidney which is used in three main situations:

(i) For temporary support of patients with the sudden onset of reversible renal failure (ie. renal function is expected to return to within a normal or acceptable range).

(ii) For regular long-term treatment of patients with irreversible renal failure, for whom the ultimate goal in most cases is a successful renal transplant.

(iii) A less common indication is for the removal of poisons from the body following, say, self-ingestion in attempts at suicide, or accidental overdosage with certain drugs. For this indication the period of haemodialysis lasts only several days.

24.5.2 During haemodialysis (use of an artificial kidney) blood is usually taken from the body by an artificial connection between a vein and an artery near the person's wrist or in the forearm. This is called an arterio-venous fistula. The blood is directed out of the body through an exchange unit (ie. the dialyser or artificial kidney) where the blood is cleansed of toxic substances and those compounds which would normally be removed by a functioning kidney. After dialysis the blood is directed back into the body via the arterio-venous fistula in the forearm or wrist.

24.5.3 Blood is prevented from clotting in the tubes of the dialyser by the use of

the anticoagulant, heparin, which is given as a continuous infusion. It is also kept warm while outside the body and maintained within a narrow temperature range not very different from normal body temperature.

24.5.4 The length of the time the patient is kept on the dialyser (artificial kidney) varies with the patient's condition and type of machine used. The average is 4 hours.

24.5.5 During haemodialysis the person is immobile and dependent on others for his needs and requires monitoring for indications of the effectiveness of the treatment and signs of any complications. Changes in blood pressure are usually recorded regularly throughout the period of haemodialysis.

24.5.6 Because of rapid changes which can occur in blood pressure and in the movements of salts and/or water into and out of the body during dialysis, and the risks of danger these may pose, there is a reasonable need for continual supervision during the periods of haemodialysis.

24.6 Continuous Ambulatory Peritoneal Dialysis

24.6.1 Continuous ambulatory peritoneal dialysis (CAPD), first prescribed in 1976, has become an accepted alternative treatment for renal failure. An indwelling catheter is inserted through the abdominal wall. Through this fluid is run, left in the abdominal cavity for 4-8 hours, and then run out. The process is repeated on a continuous basis. Treatment is therefore continuous not sessional.

24.6.2 A bag of dialysis fluid, after being warmed to body temperature, is suspended from a hook and attached to the catheter. The patient sits down and the fluid is run in. When the bag is empty, the connecting tube is clamped and disconnected. The patient is then able to go about his normal activities. After 4 to 8 hours the patient reconnects the bag, removes the clamp from the tube and allows the fluid to run into the bag. Thereafter a new bag of dialysis fluid is attached and the cycle repeated. Connection and disconnection must be carried out using a meticulously aseptic (germ-free) technique to minimise the risk of peritonitis.

24.7 Continuous Cycle Peritoneal Dialysis (CCPD) and Peritoneal Rapid Overnight Dialysis (PROD)

24.7.1 Continuous cycle peritoneal dialysis is an alternative to CAPD. A machine is used to deliver a pre-set amount of warmed fluid via a catheter into the peritoneal cavity where it remains for a time, at the end of which it is automatically removed and replaced by a further volume of fluid. The process is continuous and silent. The machines used tend to alarm frequently for various reasons, eg. the catheter may be kinked or a "systems error" has occurred. When the machine alarms all results have to be recorded and the machine re-set.

24.7.2 The patient is connected to the machine using an aseptic technique and

dialysis takes place over 10-12 hours at night in the patient's bedroom. The patient loads the machine with bags of fluid before retiring, connects it to the indwelling abdominal catheter, disconnects it in the morning, both procedures being performed with a meticulous aseptic technique, and then disposes of the waste fluid down the domestic toilet.

24.8 Care Needs

24.8.1 As CAPD and CCPD are designed to be carried out by the affected individual alone, an adult who is otherwise physically and mentally fit should not require attention or supervision to complete the process. Supervision should not be needed on account of the risk of an attack of peritonitis because, although this requires immediate medical attention, there is sufficient warning for the person himself to summon medical help.

24.8.2 In the many cases complicated by extremes of age, blindness, mental impairment, or severe physical weakness preventing the lifting of the bags of fluid it is unlikely that the affected individual will be able to complete the process without a great deal of help. In these cases, the complicating condition as well as the dialysis will have an effect on the overall care and mobility needs.

24.8.3 The occurrence of the following disabilities in those undergoing CAPD or CCPD will likely require assistance from another one or more times a day:

(i) Severe physical weakness from any cause (eg. anaemia, which is common in renal failure); help will be needed with the lifting of the bags, which are heavy.

(ii) Blindness: the bags must be checked to make sure they are clear. Clouding may be a sign of infection or fibrin formation. The latter can block the connecting tubes and is dealt with by an injection of heparin into the bag.

(iii) Loss of manual dexterity: the changes of the bags needs considerable manual dexterity and must be carried out under meticulous aseptic conditions. The function of the hands is very important. Persons with moderate to severe arthritis of the hands (eg. rheumatoid arthritis) may well not be able to perform the actions without the assistance of another person.

(iv) Extremes of age: the very young and the very old may well need assistance with the changing of the bags.

24.8.4 Night attention is not normally needed on account of dialysis alone as the dialysing fluid is left in the abdominal cavity overnight, changes taking place during the day.

24.9 Mobility Considerations

24.9.1 Those doing well on dialysis should be able to walk.

24.10 Duration of Need

24.10.1 Chronic renal failure is irreversible. In its late stages its effects are alleviated only by dialysis or by renal transplantation. For those starting on haemodialysis, the needs are likely to continue unchanged unless a transplant takes place. For those on CAPD or CCPD who need assistance because of other problems, the duration of need will depend on the outlook for the other cause of the disability.

24.11 Renal Transplantation

24.11.1 In the majority of instances following a transplant there is a return of normal renal function. This is usually immediate but may take up to three weeks. This return of function leads to a rapid improvement in the person's condition. Following transplantation patients need frequent follow-up at hospital outpatients with regular blood testing. However they should not have any significant care or mobility needs.

24.11.2 The danger following transplantation is that the new kidney will be recognised by the person's immune system as foreign and be rejected. Acute rejection occurs 1-12 weeks after transplantation. This can be treated successfully with immunosuppressive drugs in many cases. Chronic rejection shows when there is a slow decline in renal function more than three months after transplantation. Treatment does not benefit this condition and a return to dialysis will be necessary whilst the person waits for another transplant. In most cases it will be known by three months after the transplant whether or not it has been successful and whether or not the person will need further dialysis.

24.11.3 At this stage, the person may still have other problems giving rise to care and mobility needs.

24.12 Further Evidence

24.12.1 All people on dialysis will be attending a hospital renal unit from whom any additional information may be obtained.

25. BOWEL DISEASES AND DISORDERS: INFLAMMATORY DISEASES INCLUDING ULCERATIVE COLITIS AND CROHN'S DISEASE; DIVERTICULAR DISEASE; IRRITABLE BOWEL SYNDROME

25.1 Contents

25.2 Ulcerative Colitis and Crohn's Disease

25.2.1 Ulcerative colitis and Crohn's disease are the commonest of a group of potentially debilitating chronic inflammatory bowel (intestinal) disorders, mostly of uncertain cause but with generally similar effects. Ulcerative colitis is an inflammation of the colon (the large or lower bowel). Crohn's disease (also known as regional enteritis) more often affects the lower section of the small bowel (ileum), but may involve any part of the digestive tract.

25.2.2 Both diseases tend to develop in younger people, usually in the late teens or twenties, although Crohn's disease can occur in childhood and there is a second "peak incidence" of onset between the ages of 50 and 70. They have broadly similar effects, which range from mild episodes of diarrhoea and abdominal pain to life-threatening acute episodes or unremitting, debilitating symptoms.

25.3 General

25.3.1 Both diseases are characterised by abdominal pain and episodes of diarrhoea with the passage of blood. There may also be more generalised symptoms such as fever, anaemia, weight loss and dehydration. Crohn's disease may also result in a deficiency of vitamins and minerals because it often affects the small bowel where these are absorbed. This deficiency is not usually a problem with ulcerative colitis because its effects are confined to the large bowel, which has a different function.

25.3.2 Although the first attack may be severe and disabling, it usually responds

well to treatment, often in hospital, leaving little disability. Further attacks, although disabling at the time, tend to be relatively short-lived, lasting for between three and 12 weeks. Between these episodes, most sufferers have only mildly disabling symptoms for periods of months or even years. For those who continue to have moderate symptoms, there is effective medical treatment.

25.3.3 A small proportion of people do not respond to treatment, be it medical or surgical (which may involve the removal of a large section of intestine) and suffer from severe weight loss and malnutrition. These people may become very disabled as a result, although this degree of disability is usually temporary as parenteral feeding [see Chapter 26] and more intensive medical treatment is likely to restore their weight and well-being.

25.4 Care Needs and Mobility Considerations

25.4.1 The majority of people suffering from inflammatory bowel disease manage to cope unaided with the essential activities of daily living, even during relapses, and have no significant mobility problems. As these diseases mostly affect adults, even those with persistent symptoms are usually able to care for themselves.

25.4.2 Those with severe disease, where treatment has failed to help, may well have qualifying care and mobility needs, particularly if there is serious malnutrition. Ulcerative colitis can cause as many as 10 to 20 episodes of diarrhoea over a 24-hour period. These often involve quite severe abdominal cramps and the passage of blood (itself a distressing symptom), and a degree of urgency verging on incontinence. Also, advancing years and the presence of other disabilities often impose additional problems.

25.4.3 The necessity for surgical treatment is usually an indication that inflammatory bowel disease is both severe and has failed to make an adequate response to medical treatment. The surgical operations most likely to be referred to in claims or other evidence are :-

(i) **ileostomy:** opening of the small bowel onto the abdominal wall where its liquid contents discharge into a plastic bag.

(ii) **colostomy:** the diversion of faeces through an opening from the colon onto the abdominal wall. The more solid consistency of the discharged material usually makes a colostomy easier to manage than an ileostomy, and not all those who have had a colostomy need to wear a bag.

(iii) **colectomy:** removal of part or all of the large bowel.

(iv) **procto-colectomy:** removal of the rectum and part or all of the large bowel. Those in whom such operations have become necessary are likely to have become frail, with some degree of

limitation in walking ability. Their physical condition may take several months to improve, even when the operation has been successful.

25.4.4 To manage an ileostomy or colostomy unaided, a person needs to be physically and mentally fit. Visual problems, loss of manual dexterity, age and mental disabilities may add sufficiently to the overall disability to make help necessary with changing the bags, and the care of the stoma (ileostomy/colostomy opening) and surrounding skin. This help will be required at least for a period of several months and maybe longer.

25.4.5 Medication, including that which has to be administered rectally in the form of small, pre-prepared enemas, is managed without assistance, except when the patient is severely debilitated, very old, very young, mentally disordered or has impaired manual dexterity.

25.4.6 Except for the small percentage of cases receiving parenteral nutrition, adults with inflammatory bowel diseases do not usually need help with special dietary regimes. Only very few gain benefit from "elimination" diets, which, in any case, are not difficult to prepare. Vitamin and mineral supplements and a reduced intake of high-fibre foods are often necessary, but can nearly always be managed by patients themselves.

25.5 Duration of Needs [see also para 25.3.2-3]

25.5.1 In people with needs arising from malnutrition, active medical treatment of the disease, sometimes with the institution of total parenteral nutrition, usually leads to an improvement in the general condition, with a significant reduction in both care and mobility needs over a period of three to six months. If after a year the situation is no better, then no further change is likely.

25.5.2 Surgical treatment is possible in most cases where severe symptoms persist despite other measures. The length of time for which qualifying care needs will persist after operation depends largely on the degree of debility at the time of operation, the age of the person and the presence of other related or unrelated disabling conditions. An ileostomy is much more likely than a colostomy to result in continuing care needs. In most cases there is rapid improvement over about three months.

25.5.3 Qualifying mobility needs are unlikely to remain for long after successful surgical treatment.

25.6 Associated Disorders

25.6.1 Some people, particularly those with ulcerative colitis, may develop arthritis associated with their bowel disease. This can add to the overall disability,

increasing and prolonging the need for help. The arthritis may affect the limb joints, the spine (spondylitis) or both, and may give rise to care and/or mobility problems [see Chapter 6]. In Crohn's, disease there may also be disabling inflammation of the eyes, mouth or skin.

25.6.2 Retardation of growth is a complication likely to affect children with inflammatory bowel disease. Children are also more prone than adults to complications like arthritis, anaemia and fever. The effects of these non-intestinal disorders sometimes actually predominate in younger patients. In any case, children with inflammatory bowel disorders, especially those below the age of 12, will have some care needs beyond those normally appropriate to their age.

25.7 Further Evidence

25.7.1 The majority of people with severe bowel disease, and all those who need parenteral nutrition, will be attending hospital. A factual report from the hospital is likely to be helpful in establishing the severity of the disability and its likely duration. In other cases a report from a general practitioner should provide any further information necessary for adjudication. If no recent factual information is obtainable from either of these sources, then a report from an examining medical practitioner will give evidence of the current situation.

25.8 Diverticular Disease

25.8.1 Diverticulosis is the presence of multiple (usually small) abnormal sac-like pouches of the lining of the large bowel through its muscular layer. It often causes no symptoms, and is not likely to cause disability unless complications are present.

25.8.2 Diverticulitis is diverticulosis complicated by inflammation. When this is so severe as to cause disability leading to care or mobility needs, definitive surgical treatment is usually offered. This may include a colostomy, but, unlike in colitis or Crohn's disease, it is usually closed a few months later.

25.8.3 When needs are claimed to have been present for more than six months, or to be likely to persist for such a period, medical advice or further evidence will be helpful.

25.9 Irritable Bowel Syndrome (IBS)

25.9.1 This condition is often mentioned in claims for DLA and AA. It is a very common disorder of intestinal motility with no anatomical disorder, more common in women, and often associated with hormonal or emotional factors like anxiety, depression or stress.

25.9.2 It is not a serious or debilitating illness, and does not give rise to care needs, except perhaps when present as one among multiple conditions. Even then, it would not be expected to make any significant contribution to mobility needs.

25.9.3 Unfortunately it is sometimes referred to by the misnomer of "Irritable Bowel Disease" and abbreviated to IBD, causing confusion with the far more serious inflammatory conditions described in earlier paragraphs. Consultation with a Medical Services doctor will, in the majority of cases, resolve any doubt over the nature of the disorder present and its probable effects.

26. TOTAL PARENTERAL NUTRITION (TPN)

26.1 Contents

26.2 Introduction

26.2.1 TPN is a method of ensuring adequate nutrition when normal absorption of food and fluid by the bowel is impossible. It is a relatively recent development in the treatment of serious intestinal conditions, such as Crohn's disease, other conditions in which it is desirable to bypass the small bowel, and conditions which have necessitated its total or partial removal.

26.2.2 A jejunostomy or ileostomy (an opening onto the skin from part of the small bowel, a stoma) is often present in people on TPN.

26.3 General

26.3.1 A fine tube (catheter) is inserted into a major vein in the neck, to remain there (indwelling), with the other end secured to the front of the chest and capped when not in use. The procedure involves passing 3-5 litres of feeding solution through the catheter with the aid of a sophisticated pump, weighing some 2-3kg, which is mounted on a drip stand. This takes about 8-14 hours and is usually carried out overnight.

26.3.2 After any necessary additions to the feeding solution have been made, the infusion is connected to the catheter. This must be done wearing sterile gloves and using the methods employed in a operating theatre, to ensure that no germs are introduced, as these could easily cause a serious and often fatal infection in the bloodstream (septicaemia).

26.3.3 The pump must be programmed accurately, as it is essential that the fluid is introduced at a constant rate, which must be slowed before it is discontinued to avoid a sudden dangerous drop in the concentration of sugars in the blood (hypoglycaemia) - [see Chapter 17].

26.3.4 The pump will detect air in the system, which could prove fatal, or blockage of the catheter for any reason, and it is of sufficient sophistication to alert the person concerned to a problem. However, it may not be possible for the person to take the necessary action, which may be required urgently, unaided.

26.3.5 After use, the infusion must be disconnected and the catheter flushed, using the same sterile procedures as during set-up. The dressing over the catheter

site will also need changing.

26.3.6 Success depends to some extent on the training given before the person leaves hospital, stressing the vital importance of attention to detail, and ensuring that confidence has been gained, both in their ability to cope with the procedure, and in the responsiveness of "back-up" systems, such as provision of fluid and equipment, GP support, and a hospital on-call advice line. Success also depends on the person having a stable personality, reasonable intelligence and considerable manual dexterity and, even given favourable circumstances, most people are admitted to hospital at least once a year because of some complication such as an infection, or displacement or blockage of the catheter.

26.4 Care Needs

26.4.1 People receiving TPN have, by definition, a serious disorder of the bowel. They may be passing 2 or 3 litres or more of fluid into a stoma bag in 24 hours which leads to fatigue. They may have other serious and debilitating effects from their underlying disease, or manifestations of associated disorders, such as arthritis. Such people will be frail.

26.4.2 The aim of TPN is to keep people alive and, where possible, independent and mobile between infusions. Some are able to go to work, depending on age and the severity of the underlying disease, or look after their family unaided. Some cannot undertake these activities but are able to cope with their own care. A very small proportion are dependent on others, to administer the treatment for them at home.

26.4.3 Because of the long duration of the procedure, their general frailty, and the weight of the apparatus, help may be needed for toiletting purposes during its course.

26.5 Mobility Considerations

26.5.1 TPN, in itself, should not create mobility problems but the underlying condition, especially if there are associated disorders, may be severe enough to do so.

26.6 Duration of Needs

26.6.1 For most people, TPN will be life-long. There may be some reduction in needs in the first year or so, as the general nutritional state improves, but initially there may be both physical and psychological reasons for support being desirable. Both physical disability and psychological adjustment need to be taken into consideration in each case.

26.7 Further Evidence

26.7.1 Everyone on TPN will be attending a hospital. A factual report from the hospital concerned may help establish the severity of the condition and the likely duration of needs.

27. DISORDERS OF BLOOD AND BLOOD CLOTTING

27.1 Contents

27.2 Anaemia

27.2.1 Introduction

(i) Anaemia is a very common condition and may be defined as an abnormally low level of haemoglobin in the blood. The oxygen carrying capacity of the blood depends on the presence of haemoglobin which is contained in red blood cells. When the haemoglobin level in the blood is reduced, the various parts of the body are deprived of oxygen, which is vital to their needs, resulting in all the symptoms attributable to anaemia. Insofar as chronic heart and lung diseases [Chapter 11] also deprive the body of oxygen, they give rise to some of the same symptoms as anaemia and will be more disabling in the presence of anaemia.

(ii) Anaemia may be due to excessive blood loss; inadequate production of normal red blood cells; excessive destruction of red blood cells, or to various combinations of these factors.

(iii) Whilst it is often possible to treat both the cause of severe anaemia and the anaemia itself, sometimes such an anaemia is a complication of a serious underlying disease (e.g. leukaemia,) which may give rise to significant disablement in its own right.

27.2.2 Care Needs

Anaemia may be slight and symptomless and is common in young women of child-bearing age, as a result of blood loss during menstrual periods. When the anaemia is much more severe the individual becomes progressively weaker and more breathless. Only in its advanced stages is anaemia likely to give rise to a need for attention or supervision in its own right, by which time breathlessness will occur at rest, or on the slightest exertion. With this degree of anaemia everyday activities may be impossible, or take an inordinate length of time to execute.

27.2.3 Mobility Considerations

Severe cases of anaemia may result in limited walking ability, due to breathlessness and this is likely to precede attention and supervisory needs. Any angina or intermittent claudication [see Chapters 11 & 13] will be rendered more disabling by the presence of significant anaemia. The presence of anaemia in the vast majority of people is unlikely to be of a severity which would result in a degree of weakness and/or breathlessness sufficient to impair walking to a significant degree.

27.2.4 Duration of Need

This is very largely determined by the cause. Whilst the anaemia resulting from blood loss can be corrected, if necessary, by transfusion, anaemia secondary to malignant disease, or renal failure, is likely to be chronic. Thus the duration of need is likely to be determined by such underlying conditions and their responses to treatment, rather than by the anaemia itself.

27.3 Haemophilia in Adults

27.3.1 Introduction

(i) Haemophilia A is the commonest of the inherited disorders of blood clotting and occurs almost exclusively in males in its active form. It affects 1:4000 of the population of Britain, although only 1:20,000 is severely affected. Other similar disorders giving rise to a bleeding tendency are Christmas disease (also known as Haemophilia B) and von Willebrand's disease. Haemophilia B has very similar effects to haemophilia A, while von Willebrand's disease usually follows a milder course.

(ii) The conditions are due to deficiencies in the blood clotting mechanism and are characterised by a life-long tendency to excessive bleeding. In haemophilia A there is either a seriously reduced level (less than 5%) or

total absence of Factor VIII and in haemophilia B a similar lack of Factor IX. The effect of this is greatly to increase the time it takes for blood to clot, so that the affected individual may bleed seriously after minor injury or in some cases, even after normal physical activity. The knee joint is most frequently affected because of the damage done to the joint and its surroundings by blood loss into the joint..

(iii) The conditions are treated by replacement of the missing clotting factor by intravenous injection, either at regular intervals or in emergencies caused by bleeding episodes. Usually, affected individuals are provided with a supply of the appropriate clotting factor and are taught to inject themselves immediately bleeding occurs. If there is bleeding into a joint (such as the knee) all that is usually required is for the joint to be rested for a few days until it has settled down. Some people attend hospital for their injections.

27.3.2 Care Needs

(i) Adults should have a clear understanding of their condition and the need to avoid injury. They should not normally need supervision to avoid the danger of precipitating bleeding episodes.

(ii) Adults are taught to give themselves the clotting factor and they should not normally require attention for this reason. If help is required because of mental impairment or arthritis of the hands affecting manual dexterity, etc. the need for injections is usually intermittent and infrequent. Even if bleeding is more frequent so that help is needed more often, the time taken to prepare and give an injection is not great and no other help should be needed. Supervision is not likely to be required as the person can ask for assistance when this is necessary. Watching over at night is unlikely to be necessary.

(iii) Repeated bleeding into joints may lead to permanent damage and the care needs may then be similar to someone with extensive inflammatory or degenerative arthritis [Chapter 6].

27.3.3 Mobility Considerations

Repeated bleeding into lower limb joints may lead to the development of arthritis with a consequent effect on walking ability. For those individuals with severe haemophilia A (less than 5% Factor VIII) or severe forms of haemophilia B there may be a significant danger of spontaneous and serious bleeding into joints during normal walking. This will need to be taken into account when mobility needs are being considered.

27.3.4 Duration of Need

If the risk of severe bleeding when walking has been established or severe joint damage has occurred the need for help will be permanent. However in some individuals knee joint replacement is an option which, when

successful, considerably improves function at the affected joint.

27.3.5 Further Evidence

People with haemophilia are invariably under the care of the haematology department of a hospital. A factual report from the hospital may help to establish the danger of a spontaneous bleed when walking and a history of bleeding episodes and any resulting disability.

27.4 Haemophilia and Human Immunodeficiency Virus Infection

Before 1985 1200 people with haemophilia were infected by preparations of Factor VIII contaminated with the HIV virus. Unfortunately a number of these people have developed symptomatic HIV infection. Care and mobility needs may result from the effects of haemophila and symptomatic HIV infection. [See also Chapter 32].

28. SYSTEMIC LUPUS ERYTHEMATOSUS

28.1 Contents

28.2 Introduction

28.2.1 Systemic lupus erythematosus (also known as lupus, L.E. or S.L.E.) is one of the so-called connective tissue or auto-immune diseases. It is a condition in which the immune system, instead of attacking intruders, such as bacteria, attacks the body. Virtually any organ in the body may be affected.

28.3 General

28.3.1 The commonest problem in S.L.E. is arthritis, affecting 95 per cent of all those with S.L.E. The arthritis is usually painful, but is rarely deforming, and the symptoms can usually be controlled by analgesics (pain-relieving drugs). Skin lesions are also common, but rarely give serious trouble. However, some people with S.L.E. are particularly sensitive to sun exposure, which may make the skin problem worse, as well as activating more serious internal disease.

28.3.2 Nearly every system in the body can be affected in S.L.E. However, the two most serious complications are renal (kidney) and neurological involvement, with or without psychiatric symptoms. Both of these complications carry a poor outlook.

(i) Kidney disease is often rapidly progressive and difficult to control, leading to total kidney failure. Dialysis is often required, and kidney transplants may well fail because the new kidney could be rejected or become affected by the disease.

(ii) Neurological involvement can take almost any form, from damage to a single nerve in the arm or leg, to major psychiatric disorder. Fits, strokes (hemiplegia) and unsteadiness and loss of co-ordination (ataxia) are all seen. Frequently disablement occurs rapidly, resulting in major care and mobility needs. Psychiatric disorder can cause major disruption to a person's way of life and put a considerable strain on carers. The prognosis for neurological involvement is generally poor as medical treatment is often ineffective.

28.4 Care Needs

28.4.1 Care needs can vary considerably. Many people with mild disease lead entirely normal lives, including following normal occupations. Others have more aggressive disease, but with rigorous medical treatment can also be little inconvenienced by their condition. The fact that a person is taking a number of apparently powerful drugs, including steroids, is not itself evidence of a requirement for help with care or mobility.

28.4.2 For the majority of those with more severe, less well-controlled disease it is relatively unusual for help to be required with normal daily activities. However, pain can be severe, and turn what would usually be simple tasks into difficult ones.

28.4.3 Kidney failure treated with dialysis gives rise to the same care needs as normally required for this form of treatment [see Chapter 24]. By the time people require dialysis, their general condition is likely to be such that they will be unable to manage CAPD [see 24.6] or CCPD [see 24.7] without help.

28.4.4 If neurological or psychiatric symptoms are present, care needs may be considerable. Paralysis, frequent epileptic fits and poor co-ordination will give rise to day and possibly night needs. If a person is exhibiting psychotic behaviour or is suicidal, considerable supervision needs will arise. [See Chapter 19].

28.5 Mobility Considerations

28.5.1 As with care needs, many people will not have significant mobility needs. However, if there is significant arthritis then mobility will be restricted. Pain may be a serious problem.

28.5.2 Mobility is likely to be restricted in the presence of neurological disease. People who have had strokes or are experiencing unsteadiness and loss of co-ordination may well be unable to walk.

28.5.3 People with major psychiatric involvement may well need supervision when in unfamiliar surroundings.

28.6 Duration of Needs

28.6.1 S.L.E. is potentially a treatable disease. Care must therefore be taken to make no hasty decisions about outcome, especially in the early stages. However, if the disease is of longstanding and still disabling, despite vigorous treatment, then it is reasonable to assume that improvement will not occur. If serious renal or neurological disease occurs, it is unlikely that the condition will improve.

28.7 Further Evidence

28.7.1 Because S.L.E. is relatively uncommon, it is usually advisable to obtain a hospital factual report. This is particularly true if major care or mobility needs are reported. Additional advice may be obtained from an occupational therapist or physiotherapist, while a community psychiatric nurse may give valuable information if neuro-psychiatric illness is present.

28.8 Other Multi-System Disorders

28.8.1 There are a number of other multi-system disorders, including systemic sclerosis (scleroderma), polyarteritis nodosa and sarcoidosis. All of these are uncommon and their effects can be widespread and variable in severity.

It is usually necessary to seek medical advice whenever a case involving any of these conditions is seen.

29. MULTIPLE ALLERGY SYNDROMES

29.1 Contents **Paragraph**

29.2 Introduction

29.2.1 A number of medical clinics have been established which lay claim to an ability to detect allergy in humans to a host of items in the food that we eat and in the air that we breathe. These allergy syndromes are reputed to cause significant disability that can only be helped by following the treatment prescribed by the particular clinic. Conventional medicine is claimed to be of no benefit.

29.2.2 Properly conducted medical trials have failed to confirm the claims made by the various practitioners in multiple allergy and the consensus of informed medical opinion is that no such condition exists.

29.3 Care Needs and Mobility Considerations

29.3.1 Symptoms said to arise from multiple allergy tend to occur in obsessional and introspective individuals and may be psychoneurotic in origin. Although many people labelled with this diagnosis claim to have significant care and mobility needs, these do not appear to be due to any underlying severe physical or mental disablement.

29.4 Further Evidence

29.4.1 A report from an examining medical practitioner may need to be obtained to try to gain a full picture of the affected person's physical and mental state and needs.

30. SKIN DISEASE

30.1 Contents

30.2 Introduction

30.2.1 The skin is frequently affected by disease, whether as primary disease of the skin itself or as a secondary effect of other conditions. There are an enormous number of different skin diseases and their classification is complex but this is not important in this context as the effects of skin disease often follow similar patterns whatever the cause.

30.2.2 The severity of skin conditions varies enormously. At one extreme there may be nothing more than a small patch of redness on a finger resulting from a sensitivity to a particular metal in a ring. At the other extreme weeping blisters may cover an individual from head to foot, resulting in fluid loss to a degree which may be life threatening.

30.2.3 Some conditions resolve, never to return, when the cause is discovered and removed, as in the case of specific allergy, whilst others follow a relapsing course throughout life requiring long-term treatment.

30.3 Care Needs

30.3.1 Even when skin disease is widespread and severe, in the absence of complications an affected adult should, to a very large extent, be able to cope with any necessary treatment unaided. Local treatment of the skin itself may require the application of lotions, creams, ointments, sprays, powders, or dressings. Only when the disease affects areas of skin which the individual cannot reach or when the hands are affected is there likely to be a need for attention. Even then, this may be brief and confined to mornings and evenings only. There is unlikely to be a need to treat the skin condition during the night hours.

30.3.2 If skin disease is secondary to other conditions there may be additional problems that make treatment more difficult. There may also be secondary problems caused by the skin disease, or by general treatments, particularly when oral steroid preparations are used. Such additional problems may have an effect on the overall disability.

30.4 Mobility Considerations

30.4.1 Mobility needs may arise when the soles of the feet are badly affected, and in those rare instances where the lower limbs have to be extensively bandaged. In addition, some skin diseases, particularly psoriasis, may be associated with a widespread form of arthritis. Involvement of the joints of the lower limbs in such cases might well give rise to mobility needs [See Chapter 6].

30.5 Duration of Need

30.5.1 By the time adult life is reached the skin disease may be long-standing and all available avenues of treatment may well have been explored. However, it is unusual for skin disease to be so serious that an adult is severely disabled by it for any length of time.

30.6 Further Evidence

30.6.1 If disability appears to be severe a factual report from the GP or hospital may help to assess the level of need. An examining medical practitioner report may also be useful in this respect.

31. INCONTINENCE

31.1 Contents

31.2 Introduction

31.2.1 Continence is the ability to pass urine/faeces voluntarily, in a socially acceptable place.

31.2.2 Incontinence of urine or faeces affects 3 million adults and half a million children in the UK. Some causes of incontinence are curable, and for most people with incontinence medical intervention can improve their quality of life. However, less than a third of affected people seek medical help, through reluctance to discuss their problem, or fear that nothing can be done.

31.3 Incontinence of Urine

31.3.1 The ability to control bladder function is normally acquired in childhood, with most children being dry both day and night by the age of 5 years. However one in 20 still have nocturnal enuresis (bedwetting) at age 5, and one in 100 adults continue to have enuresis.

31.3.2 Incontinence of urine can occur in any age group. The four main types are **stress, urge, overflow, and functional** incontinence.

31.3.3 **Stress incontinence** usually occurs in women, as a result of weakness of muscles in the pelvis or at the neck of the bladder. It results in leakage of urine in certain specific situations, such as when coughing, laughing or sneezing, or during exercise. It tends to affect older women, particularly after the menopause, and the tendency may be increased by stresses to the pelvic muscles during childbirth.

31.3.4 **Urge incontinence** is the result of instability of the bladder muscles, and is more common in older people. It results in an urgent need to pass urine at frequent intervals both day and night; incontinence results if there is delay in reaching a toilet or suitable receptacle. Urge incontinence may result from a problem with the bladder itself, or it may arise as a consequence of damage to the central nervous system and nerves controlling bladder function.

31.3.5 **Overflow incontinence** occurs when the bladder fails to empty completely; urine builds up and in the end overflows resulting in either intermittent or continuous dribbling. It may result from obstruction to the neck of the bladder, as occurs in older men due to enlargement of the prostate gland at the base of the bladder. It may also result from disease or injury of the brain or spinal cord, eg multiple sclerosis, traumatic paraplegia, which affects the nerves that control bladder function. In such cases there may be complete lack of control of bladder function.

31.3.6 **Functional incontinence** is the passing of urine in inappropriate places. It may be a result of varying degrees of immobility, for example making it difficult or impossible for the person to reach a toilet or to manage their clothing. It may also be the result of disturbed mental function, eg. dementia, severe behaviour disorders, in which normal awareness of acceptable social behaviour is lost.

31.4 Incontinence of Faeces

31.4.1 The most common cause of bowel incontinence, particularly in elderly people, is constipation with "overflow", leakage of bowel mucus around a mass of hard faeces which has built up in the rectum (lower bowel).

31.4.2 True incontinence of faeces may occur as a result of damage to the anal muscle which controls bowel actions; this may occur for example as a result of a difficult childbirth. It may also occur with disorders causing diarrhoea, where leakage can occur if a toilet cannot be reached in time to meet an urgent need to defaecate. The most common causes of prolonged diarrhoea are bowel disorders such as ulcerative colitis, Crohn's disease or irritable bowel syndrome; and psychological disorders resulting in excessive or inappropriate use of laxatives.

31.5 Care Needs

31.5.1 If the underlying cause of incontinence of urine or faeces cannot be cured or controlled by medical intervention, the person with incontinence will need to manage the condition by the use of aids such as incontinence pads and waterproof pants; or of appliances such as penile sheaths or catheters (tubes passed into the bladder at intervals to drain it of urine).

31.5.2 Younger people with normal manual dexterity and mental function will usually be able to manage aids and appliances without help; but elderly people, particularly if they have impaired manual dexterity, may need help.

31.5.3 People, particularly those in older age groups, with impaired mobility, who have difficulty in and out of bed or a chair, or whose walking ability is

substantially reduced, may need help to reach a toilet or commode in time to prevent incontinence. Since urge incontinence can occur both by day and at night, help may be needed on more than one occasion during the night. Help may also be necessary to change wet or soiled garments or bedclothes. People who are incontinent and whose mobility is impaired may be more prone to pressure sores if left in wet clothing or bedding. Frequent changes of clothing and bed linen may be required if the condition cannot be otherwise managed.

31.5.4 Persons with severe behaviour disorder or dementia will need to be reminded to use the toilet or commode at regular intervals to avoid incontinence. They are also likely to require help to manage incontinence aids.

31.5.5 Children with **enuresis** (persistent bed-wetting) are usually unaware of the wet bed. Most parents accept enuresis as a normal phenomenon, and it is not common practice to change children's bedding during the night on a regular basis. Some parents become intolerant of their children's wetting, and may suggest incorrectly that it is deliberate, or a result of laziness. This attitude can lead to secondary emotional disturbances in the child.

31.6 Mobility Considerations

31.6.1 People with incontinence may claim to have restricted mobility because of their need to be within easy reach of a toilet. This is not however a condition which of itself causes any difficulty with walking.

31.7 Duration of Needs

31.7.1 Where care needs arise as a result of incontinence, the underlying condition is unlikely to improve with time.

31.8 Further Evidence

31.8.1 People, particularly in younger age groups, who rely on incontinence aids or appliances may receive help and advice from a specially trained community nurse, from whom further information can be sought.

32 HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

32.1 Contents

Related conditions considered in other chapters

32.2 Introduction

32.2.1 Infection with human immunodeficiency virus occurs when infected body fluids are transmitted between individuals. This can occur during sexual intercourse, both heterosexual and homosexual, through transfusion of infected blood or blood products including shared hypodermic needles used by drug addicts and from mother to baby. The transmission from mother to baby may take place around the time of birth or through breast milk.

32.2.2 There is a world wide epidemic of HIV infection with the majority of cases occurring in the developing countries. In the early 1980s most cases in the UK were found in homosexual men and injecting drug users. An increasing proportion of new cases resulting from heterosexual transmission has been noted in the UK over recent years.

32.3 General

32.3.1 The effects of HIV infection on the body are gradual and progressive, usually over some years. The main effects of the virus are to cause a gradual reduction in the body's defence mechanisms against other infections and to compromise the body's normal protective mechanisms against the development of malignant disease. This is described as an **impairment of immunity** or **immunosuppression**. The types of infection which occur are often of an unusual nature resulting from organisms (germs) which do not commonly affect

normal individuals, for example, severe fungal infections such as Pneumocystis carinii pneumonia (PCP), tuberculosis or parasitic infections. These infections known as **opportunistic infections** can have a grave prognosis and be difficult to treat. Similarly the malignant tumours which develop may be of an uncommon nature. The virus can also attack the nervous tissues including the brain, and this may result in the premature development of dementia.

32.3.2 Individuals with HIV infection are divided into four groups according to the stage of their infection:

Group I	Primary HIV infection
Group II	Asymptomatic phase
Group III	Persistent generalised lymphadenopathy
Group IV	Symptomatic infection (includes AIDS defining conditions)

32.3.3 Following an interval of about six weeks after the initial infection a short lived illness (group I) with fever and rash may occur. Subsequently antibodies to the virus can be found in the blood and detection of these forms the basis of the HIV test.

32.3.4 It may be many years before any further manifestations of the disease become apparent; the individual is symptom free and leads a normal life. This phase (group II) can last for ten years or more. As time passes some people may develop generalised enlargement of groups of lymph nodes (glands) in different parts of the body (group III). Many people remain symptom free and relatively well, although others may suffer from a general lack of well being and feelings of ill health. The latter group is however unlikely to have substantial care needs or restrictions in mobility.

32.3.5 As the individual's immunity starts to be compromised unusual infections occur that may be difficult to treat, persistent diarrhoea develops and there are general feelings of debility and fatigue (group IV). Skin and mouth conditions may cause symptoms. In later stages there can be profound weight loss, generalised weakness and persistent fevers and sweats. Drug treatment (see below) however can cause partial or complete resolution of these severe manifestations. Malignant disease of the lymph glands (lymphoma) and Kaposi's sarcoma - a type of malignancy, which can infiltrate the skin and other body linings with purple/blue nodules - may supervene. Other severe manifestations of the illness include tuberculosis, toxoplasmosis, cytomegalovirus, cryptosporidiosis, meningitis, encephalopathy and dementia (**see glossary**).

32.3.6 The treatment of HIV and AIDS has been revolutionised as a result of new drug treatments. Average life expectancy has increased significantly and the death rate is falling in developed counties such as the UK. Innovative **anti-viral drugs** have been developed which are given together - three, four or even more drugs are combined in a complex daily regime, which may be taken for prolonged periods of time - months or years. These drugs reduce the viral load (see below), boost immunity to infections and increase the length of symptom free existence. It is likely that the prognosis will continue to improve year on year as further drugs are developed.

32.3.7 Blood tests are used to assess the progression of the disease and the response to drug treatment. The amount of virus in the blood stream can be calculated and expressed as the **viral load**. Over 50,000 copies/ml indicates significant disease and 150,000 or more suggests that there will be severe problems. Another blood test the **CD4 count** is a measure of the body's resistance to infection. Normal CD4 count is over a 1000 x 10^6 cells/litre; when this falls to below 200 there is a risk of developing a severe infection such as Pneumocystis carinii pneumonia (PCP). Below 100 repeated serious infections can occur. A low CD4 count combined with a high viral load can indicate a very grave prognosis in the absence of a response to drug treatment.

32.3.8 Prior to the development of effective drug treatment the results of blood tests were a useful indicator of the progression of the disease and its severity. Results of blood tests should now be interpreted with medical advice taking into account the history of the illness and whether there has been a favourable response to drug therapy. They do not bear a direct relationship to the degree of disability or the prognosis.

32.4 Care needs

32.4.1 For a number of years HIV infected individuals remain free of symptoms and are well. As immunity decreases minor skin conditions - such as persistent warts, molluscum contagiosum, impetigo, folliculitis, seborrheic dermatitis - may develop but which in themselves will not lead to a need for attention from others.

32.4.2 Some people may describe debilitating side effects arising from the drug treatment regimes. These may include nausea, headaches, skin rashes and numbness of the hands and feet due to peripheral neuropathy (inflammation of nerves). Many of these symptoms are

transient and can be controlled. More serious side effects of the drug treatment regimes do occur including weakness of the hands and feet due to peripheral neuropathy, anaemia and lipodystrophy (fat redistribution causing altered body shape). These can exacerbate disability.

32.4.3 Generalised lymph node enlargement combined with fever, malaise, sweats, weight loss and persistent diarrhoea may lead to the need for help with bodily functions in the course of the day. An individual may require help with changing bedding at night if he or she suffers from severe night sweats and general debility.

32.4.4 In more advanced disease a general poor state of health associated with repeated infections may lead to a state of overall debility and increasing care needs. Neurological complications affecting the spinal cord and peripheral nerves may lead to weakness of the limbs, pain and numbness of the hands/feet and poor balance. Help may be necessary to rise from a chair or manage at the toilet.

32.4.5 Changes in the brain may lead to poor concentration, memory loss, confusion, and fluctuating levels of consciousness and ultimately dementia. These problems may lead to a requirement for high levels of supervision. Certain infections such as cytomegalovirus and toxoplasma may affect the eyes and cause significant visual impairment.

32.4.6 The debilitating effects of tumours such as lymphomas may be exacerbated by the side effects of chemotherapeutic agents used in treatment. Anaemia and other blood abnormalities increase debility and predispose to infection and bleeding tendencies.

32.4.7 All these physical impairments may be accompanied by symptoms of anxiety and depression, which may arise following the diagnosis or become more prominent as disability increases. Disfiguring effects of the illness may exacerbate psychological impairment.

32.5 Mobility Considerations

32.5.1 Shortness of breath, neurological disease and weight loss may significantly restrict the ability to walk in the late stages of the disease. Chest infections such as pneumonia (PCP) and tuberculosis may cause breathlessness. An unusual form of tuberculosis - due to organisms such as Mycobacterium avium intracellulare - can be

difficult to diagnose. Infections of these types however tend to respond well to conventional treatment in combination with anti-viral drugs and breathlessness can improve.

32.5.2 Significant visual impairment may contribute to the need for some guidance or supervision when walking out of doors.

32.6 Duration and Prognosis

32.6.1 With the advent of greatly improved drug treatment for HIV many individuals will live for many years without significant disability.

32.6.2 As immunity starts to diminish more serious or repeated infections, or the development of malignant disease, occurs. In assessing the degree of disability it is necessary to bear in mind the stage of the illness and the fact that some of the conditions will respond to appropriate drug treatment with improvement of function. Medical Services will be able to assist in interpreting complex hospital reports including the results of blood tests. Over time however as immunity declines care needs and mobility needs will increase.

32.6.3 As the disease progresses drug treatment may become less effective or a malignant condition such as lymphoma appears. This may indicate a much graver outlook. In determining that such a stage has been reached a factual report and advice from Medical Services are required.

32.7 Further evidence

32.7.1 Obtaining and interpreting further evidence in HIV/AIDS is of particular importance, since the condition can have varied and unusual clinical manifestations causing differing degrees of disability. For many people the life expectancy has increased dramatically with new antiviral treatments, and HIV infection should be considered to be a long-term (chronic) illness managed with medication. Interpretation of medical evidence including blood tests requires knowledge of the progression of the illness and response to treatment.

32.7.2 Most people are under the regular care of a hospital clinic, and a report can be obtained from the medical attendant or specialist nurse attached to the clinic. Those with increasing degrees of disability may have been assessed by an occupational therapist, who can provide a factual report. In some cases general practitioners have comprehensive information, but they may lack recent, up to date

information if the person attends a clinic regularly. An EMP report can be useful to assess care needs or mobility when the condition appears stable and/or factual reports do not supply sufficient clinical information to enable Medical Services to advise.

32.8 Haemophilia Complicated by AIDS

32.8.1 For Haemophilia complicated by AIDS see Chapter 27

33. NORMAL DEVELOPMENT AND DISABILITY IN CHILDREN

33.1 Contents: **Paragraph**

33.2 Introduction

33.2.1 In order to understand disability in children and where the consequent needs differ significantly from those of a non disabled child it is necessary to have an understanding of the normal development process. The sequence of development is normally the same for all children, eg they sit before they can walk etc, but the rate of development varies. For example, up to 10% do not crawl before they walk but "bottom-shuffle", creep, roll, or just stand and walk. This may occur in those children who have an inherited pattern of low muscle tone and there is usually a history of affected relatives. Most children walk (even if its only a few steps) by the age of 2 years. The median age (ie the most commonly encountered age in years) of walking in shufflers, creepers and rollers is several months later than for crawlers and a few are still not walking by the age of 2, but eventually they function normally, with walking established by the age of 3 years in the majority of these children. Those who just stand and walk also have low tone and a similar family history but walk a month or two earlier than the crawler.

33.2.2 Development may be divided into four broad categories:

(i) Vision and manipulation
(ii) Hearing and speech
(iii) Gross motor skills
(iv) Social behaviour

The table at the end of this chapter gives some examples of the normal development by chronological age of healthy children during the first six years of life in each of these main developmental areas.

33.2.3 Disability or disease in a child has a great impact on parents and the immediate family. Chronic illness or disability in the infant or young child may produce considerable additional care needs - usually provided by the parents themselves. Increasing numbers of children receive high dependency care provided at home over long periods.

33.2.4 The attention which is given, particularly to infants and very young children

with disabilities, may **differ in kind** from that given to healthy children of the same age; but this may not mean that the amount of attention given is in excess of that usually required by a healthy child of the same age. Many healthy children waken at night for a variety of reasons and require attention. Likewise young children who are not disabled require care in relation to bodily functions such as eating, washing, dressing, undressing, and using the toilet. Some children, however, may not be receiving the attention they need as a result of their disabilities. The particular circumstances and needs in each case must be individually assessed and considered.

33.2.5 Assessment of care needs is also influenced by the fact that children develop both physically and mentally. This may result in decreased care needs; on the other hand, some care needs may increase. Physical development of the upper limbs in a child with defective lower limbs may enable him to move independently with mechanical aids where these are used. Increasing maturity may lead some children with chronic illness or disabilities (eg. the child with diabetes mellitus, or with cystic fibrosis, or arthritis, etc) to assume responsibility for the care of his condition and so require less supervision. Training received may also have its effect, notably with blind and deaf children. On the other hand, physical development may increase the burden of disablement: a child with learning disability may require more rather than less supervision as he gets older and becomes more mobile. Adolescents with disabilities will also have to cope with care and/or mobility needs against a background of changing patterns in body functions, social attitudes, and sometimes non-conforming and "rebellious" behaviour commonly encountered at this time.

33.3 The Care Needs of Infants

33.3.1 The Non Disabled Infant

An infant for the purposes of this text is taken to be a child aged less than one year old. Healthy infants require a great deal of attention in connection with their bodily functions. They must be fed, winded, changed and bathed frequently. In addition, if emotional development is to proceed normally, an infant must be handled, cuddled, talked to and played with regularly. Furthermore, during the times when the infant is sleeping periodic checks are made to ensure that all is well.

33.3.2 The Infant with Disabilities

Because of the amount of care and supervision/watching over required by a

healthy infant, that required by an infant with disabilities may not usually be much greater than that needed by a healthy child. The kind of attention given may differ: for example, instead of being handled in an ordinary manner, the infant with disabilities may need more specific stimulation or formal passive movements of the limbs in the form of physiotherapy, but the amount of care or supervision/watching-over may not be greater than that given to a healthy infant.

33.3.3 Disabilities Posing Very Substantial Needs

Infants with certain disabilities will require considerable amounts of stimulation, care or supervision, in addition to the normal care routine. These disabilities include:

(i) Infants with frequent loss of consciousness usually associated with severe fits secondary to birth asphyxia or rare forms of congenital metabolic disease.

(ii) Infants with severe impairment of vision and/or hearing. (Unless there is reason to suspect that a baby may be born with hearing impairment, and has been checked with special techniques, it is unlikely that hearing loss will be picked up until the child is several months old).

(iii) Infants with severe multiple disabilities.

(iv) Other categories of infants with disabilities may well require extra care: infants with renal failure [Chapter 24], with cystic fibrosis [Chapter 44], with asthma [Chapter 45], with cerebral palsy [Chapter 40], and those survivors of extremely pre-term birth.

(v) Infants with severe feeding problems which are due to physical reasons, such as oro-facial malformations (eg. cleft palate), or cerebral palsy.

(vi) Some infants with developmental delay/learning disabilities who require prolonged periods to take adequate amounts of each feed. Some children with Down syndrome may fall into this category.

33.3.4 Care Involving Technical Procedures

The care of some infants with disabilities involves the use of technical procedures such that the attention or supervision/watching-over required from birth may be greatly in excess of that required by a healthy infant.

These include:

(i) Infants requiring regular mechanical suction because they have a tracheostomy or other upper airway problem.

(ii) Infants being fed by tube into the stomach or a vein.

(iii) Infants who need oxygen regularly in order to survive. These include infants with bronchopulmonary dysplasia (impairment of normal lung development and impaired lung function) as a result of very premature birth.

(iv) Infants with one of the following surgical procedures whereby a segment of the stomach or bowel is opened up onto the abdominal wall for feeding or for the elimination of waste: gastrostomy (the stomach has an opening onto the abdominal wall to assist in feeding by tube); ileostomy; jejunostomy; colostomy (all these are connections between a particular part of the bowel and the abdominal wall. They are usually constructed to form an exit from the intestine when part of it is blocked or has been destroyed by disease).

(v) Infants with a nephrostomy (a connection between the urinary tract and the abdominal wall, constructed to form an exit for the passage of urine).

33.4 The Older Infant/Young Child

33.4.1 The Non-Disabled Infant

As the healthy infant gets older the emphasis shifts from attention to supervision. Feeds become less frequent; winding is no longer necessary; the child begins to feed himself. However, from the age of about six months the development of investigative skills in tandem with increasing mobility puts the healthy child at risk of danger; the level of supervision required to avoid danger is considerable.

33.4.2 The Infant With Disabilities

At this stage (often between 9 and 15 months), the gap between the care needs of a healthy child and a child with disabilities may have widened to the extent that the needs of the child with disability are significantly in excess. These may include continued attention to bodily functions no

longer required by the healthy child, and more attention than needed by the healthy child for the development of new skills such as crawling, standing, and walking. The age at which the need for attention of the child with disability becomes greater than that of the healthy child cannot be defined precisely and judgement will depend on the evidence available in the individual case.

33.4.3 Disabilities Posing Substantial Needs

There will be some children with disability with needs persisting or first manifesting at a level in excess of the norm at this age, for example:

(i) children with brittle bones [osteogenesis imperfecta - see Chapter 46], haemophilia [Chapter 47] and other severe bleeding disorders, in whom bumps and falls are associated with the risk of fractures or haemorrhage.

(ii) mobile children with hearing and/or visual problems who cannot respond to a warning shout or see a potential danger, which a healthy child would avoid.

(iii) children with cerebral palsy whose mobility is impeded and whose risk of postural deformity is reduced by frequent changes in position by parents.

(iv) children with a severe learning disability who eat undesirable substances (pica) or exhibit self-mutilation behaviour. A child with severe learning disabilities may also require substantially more stimulation to maximise potential.

(v) children in whom developmental delay may first become evident because of a need to continue a level of attention appropriate for a much younger baby.

33.5 The Older Child and Adolescent

33.5.1 The variety and level of care needs and mobility requirements in the older child and adolescent with disabilities are dependent not only on chronological age but also on a number of other complex and interrelated factors which arise not only from the disabilities themselves but from consideration of the circumstances operating in the individual

child/adolescent. Information on the care needs and mobility requirements likely to arise in the older child and adolescent are dealt with in the context of the remaining chapters of this section devoted to disabilities in children.

33.6 Night Needs in Infants and Young Children

33.6.1 Healthy children **under the age of two years** normally require a considerable amount of attention, both in frequency and duration, during the night hours, for feeding, changing, or "settling" - the latter especially during teething. Specific, regular attention at night in excess of the norm may be required by some children with disabilities whose medical condition calls for parental intervention in the form of turning, nebulizer or oxygen therapy, suction, intubation, care during fits, etc. The majority of such disabled children have already been described under paragraphs 33.3.3 and 33.3.4.

33.6.2 If precautions are taken at night (such as the child being safely placed in a cot with sides, and bumpers if required and used) there may be few conditions requiring watching-over in the absence of attention needs which are substantially in excess of those needed by a child of comparable age.

33.6.3 However, the need for watching over in excess of normal will depend on the evidence available in an individual case. Notably, children with severe learning difficulties may have an abnormal tendency to develop a persistent habit of night wakening. In such cases attention from parents may be required more than once a night, and may last one hour or more.

33.7 "Difficult" Children

Some healthy children are described by their parents as 'difficult' because they require more attention or supervision than other children of their age. However the increased needs here may not necessarily arise from severe physical or mental disability. It is however important to determine that children with disruptive behaviour at home have been assessed properly to ensure there is not a physical, intellectual or other reason for their behavioural problems. [See also Chapter 36].

33.8 Duration of Need

33.8.1 It is not possible to give generalisations on the duration of needs. This will depend entirely on the particular disability or disabilities for which the child has care and/or mobility needs.

33.9 Further Evidence

Most Child Development Centres provide parents with a report on the child's assessment which may be a useful source of additional information, should this be required. A report from the GP or hospital may also help in determining the level of disability and the likely duration of care needs. By the age of six the child may have been in some form of education for a year and assessment of potential will have been made. At that time, a school report may help in determining the level of any

continuing care needs and their likely duration.

34. SEIZURE DISORDERS IN CHILDREN

34.1 Contents

34.2 Introduction

34.2.1 Seizure disorders affect approximately 1 in 200 children. In the majority of children with seizure disorders, the condition responds very well to treatment and the care and mobility needs should not differ significantly from those of normal children. Where seizures are not controlled, however, the situation will be different. There are, in addition, a number of rare, but well defined seizure disorders which occur in children and which give rise to very severe and intractable fits and where the need for supervision is consequently much greater.

34.3 Care Needs and Mobility Considerations

34.3.1 Factors influencing care needs in children with epilepsy are similar to those for adults [see Chapter 14] and include:

(i) The duration of the epilepsy.

(ii) The nature of the attacks.

(iii) Whether the child get any warning or aura. This will rarely be manifest in a small child; older children may have some premonitory symptoms recognisable by carers.

(iv) The duration of the loss of consciousness or altered awareness.

(v) Whether there are convulsive attacks.

(vi) Whether the child is incontinent.

(vii) Whether an attack is followed by confusion or automatic behaviour. This tends to be more frequent than in adults, but less dangerous, except in adolescents.

(viii). The frequency of the attacks.

(ix) When the attacks usually occur.

(x) The type of treatment the child is receiving and what effect it has had. Treatment is effective in most children although, as in diabetes, there may be a period of poor control at the beginning of puberty. In addition there are a number of rare, but severe seizure disorders in children where it is very difficult to control the fits with any form of treatment.

(xi) Whether the child has ever been injured.

(xii) Whether the child has experienced status epilepticus or serial epilepsy [See Chapter 14]. These are of much more serious import than in an adult.

(xiii) The presence of any associated developmental disorder. One third of children with epilepsy also have severe learning difficulty, autism, or cerebral palsy.

34.3.2 A child is not usually able to understand epilepsy and to sensibly regulate activities to minimise the danger from fits. There is, therefore, a greater risk. The degree of danger depends to a large extent on the frequency and severity of the fits. In general terms, if a child is having major fits more than once a week the danger is significant.

34.4 Duration of Need

34.4.1 Epilepsy is treatable and many children improve dramatically, and are able to attend normal school and take part in everyday activities freely. It is not possible to give generalisations on the duration of the need which will depend on the particular features of the individual case. However, long-term disability is seldom seen unless the epilepsy is associated with other neurological conditions or learning disability.

34.5 Associated Conditions

34.5.1 In those cases in which there is an associated condition (birth injuries, cerebral damage, both accidental and non-accidental, inborn errors of metabolism,) this is often the main cause of disability, rather than the fits. Both the underlying condition and the epilepsy will have an influence on the whole picture determining the care needs. It is possible that, taken in isolation, neither the physical disability nor the fits require attention and/or supervision/watching-over or give rise to mobility problems but together they may do so.

34.6 Febrile Fits

34.6.1 These are not uncommon in small children (up to 4-5 years) but decrease dramatically thereafter. They occur when the child develops a high temperature associated with an acute infection and they do not occur at other times. The risk of fits is, therefore, intermittent and can be minimised by appropriate preventive measures. Because of this febrile attacks by themselves are very unlikely to require attention and/or supervision/watching-over for a long time.

34.7 Further Evidence

34.7.1 In most cases a factual report from the GP or hospital should provide all the information needed. In cases where the epilepsy is associated with other conditions, particularly learning disabilities, a report from the school the child attends is likely to give a better picture of the overall need.

35. CHILDREN WITH MENTAL RETARDATION/LEARNING DISABILITIES

(Alternative Terms: Mental Impairment, Mental handicap, mental subnormality

35.1 Contents **Paragraph**

35.2 Introduction

35.2.1 Mental retardation/learning disability is a condition of arrested or incomplete development of mind. It is characterised by delayed development of skills, eg. language, thinking and movement and social skills. Adaptive behaviour is impaired, and the risk of exploitation is increased. Educational progress is limited. Mentally retarded children have an increased rate of other psychiatric disorders, and in particular, may show significant behavioural problems.

35.2.2 Mental retardation is divided into mild (IQ 50-69), moderate (IQ 35-49), severe (IQ 20-34), and profound (IQ less than 20).

35.3 Mild Mental Retardation

35.3.1 Most children with mild mental retardation acquire adequate speech for conversation and are able to care for themselves eventually, but their development will be delayed. Such children will require ordinary care which may need to continue for slightly longer than with normal children. Some special educational input is likely to be needed.

35.4 Moderate Mental Retardation

35.4.1 Children with moderate mental retardation are slower in developing; some will not achieve the ability to care for themselves. Unless associated with autism [See Chapter 37], or other psychiatric problems, such children would be able to communicate with others, and enjoy simple social activities. Care would be required for significantly longer than normal children, though the nature of the care would be much as for a normal younger child. There is an increased incidence of epilepsy in such children.

35.5 Severe Mental Retardation

35.5.1 Children with severe mental retardation have more limited development, with no prospect of eventually caring for themselves. There are often associated neurological problems affecting mobility. One third have epilepsy.

35.6 Profound Mental Retardation

35.6.1 Such children are severely limited in their communications; they may be immobile, or incontinent. They have no ability to care for their own basic needs, and require constant help and supervision. Two thirds have epilepsy: associated cerebral palsy and sensory impairment are common.

35.7 Care Needs

35.7.1 In children with mild mental retardation, the care needs of the child are unlikely to be significantly different from those of a normal child. At the severe end of the continuum, children will require constant attention for all their bodily needs, with no prospect of significant improvement. Between the two extremes, the extra care required for the child because of his or her mental retardation, will vary not only according to IQ, but also according to associated factors, eg. physical disorders, epilepsy, behaviour problems.

35.7.2 Generally, all children with moderate or greater degrees of mental retardation, are likely to have care needs significantly in excess of those for normal children for a period of their development; some of these children will improve, while others will fall further behind with time. Children who fall into the category of severe mental retardation will be heavily dependent on others for their daily care, and will remain so.

35.7.3 In addition to care needs, many moderately and severely retarded children will require extra stimulation to improve their development progress, as they are less able to seek and create varied and stimulating experiences for themselves.

35.8 Mobility Considerations

35.8.1 Mildly retarded children are not likely to have special mobility needs. As the degree of mental retardation increases the risk of associated physical disability also increases, and mobility needs may arise from these associated difficulties.

35.8.2 More severely retarded children are likely to place themselves at risk (from traffic, or strangers) if out alone, and may therefore need to be accompanied when out in order to be safe.

35.9 Further Evidence

35.9.1 If an IQ assessment has been undertaken by an educational, or clinical psychologist, this can be a useful guide, though often no full IQ assessment will have been made.

35.9.2 A report from a developmental paediatrician, paediatric neurologist, or psychiatrist specialising in mental retardation, may be helpful in establishing the degree of the problem.

35.9.3 A copy of the Statement of Educational Needs should prove helpful, and a report from the nursery, school, or special educational unit, should also provide useful information on care and mobility needs.

35.10 Down Syndrome

35.10.1 Introduction

(i) Down syndrome is the most easily recognisable cause of learning disability in children and consequently is discussed in detail here. It is a congenital condition, caused by the presence of an extra chromosome in addition to one of the normal pairs. In 8% of affected children the extra chromosome is attached to another chromosome (translocated), usually number 14 or 21. Occasionally children show milder forms when only some cells are affected (mosaic) or only part of the chromosome 21 exists in triplicate. The syndrome is usually recognisable at birth by very lax muscle tone (hypotonia) and a characteristic physical and facial appearance.

(ii) Intellectual impairment is always present, though the degree is variable. Learning difficulties range from quite mild to very severe, but are usually moderate/severe. Social and practical skills may be acquired which mask the severity of the problem. Simple literacy skills may be developed by some, but usually with limited comprehension. The limitation of reasoning ability is such that few are able to achieve full social independence, though most learn several self-care skills.

(iii) Behaviour problems may exist, in the form of overactivity, mischievousness and sometimes stubbornness. Other behaviour problems which are common in children and adolescents with Down syndrome include passivity, tantrums, disorders of continence eg soiling, and lack of inhibition which can put individuals at risk. Aggression and violence are rare. Psychiatric disorders such as depression and autism are commoner than in the general population.

(iv) Speech and language problems are a particular feature, due not only to intellectual factors, but to physical ones as well. The shape of the palate, small mouth cavity, relatively large tongue and tendency to nasal speech

lead to poor pronunciation of words. Recurrent ear infections, causing intermittent and variable hearing impairment, commonly add to the difficulties. The speech may be insufficiently clear to be understood by strangers.

(v) Many systems or organs may be affected by congenital abnormalities. Heart malformation is present in about 40% of children with Down syndrome. This is variable in degree and effect, ranging from a small "hole in the heart" causing no problem other than the need for antibiotics to be given when dental procedures are undertaken, to complex disorders giving rise to heart failure and reduced life expectancy. Congenital abnormalities may occur in the digestive tract. Cataracts occur more often than in the general population, as do the common visual defects requiring spectacles to be worn.

(vi) Children with Down syndrome are prone to frequent recurrent infections, particularly of the respiratory tract and middle ear. The latter often lead to accumulation of sticky fluid ("glue ear") which impairs hearing.

35.10.2 Developmental Progress

(i) The child's development follows the normal pattern, but there is usually some delay in acquiring skills from the outset. At first the delay may not be obvious, especially if the child is actively and constantly encouraged to learn the skills which would come easily to a normal child. By about school age, however, progress has usually slowed. The overall rate is adversely affected by factors such as the presence of associated disorders, (see above), and it is not unusual for the acquisition of relatively simple skills to continue into adult life.

(ii) Sitting, in children without associated disabilities, is usually achieved by about a year old, standing by 18-20 months, and walking by about two, though it may take considerably longer for full stability and co-ordination to develop.

(iii) Communication skills are acquired particularly slowly. Single words often fail to appear until the age of about two, and simple sentences may be delayed to school age and beyond. In many cases real fluency is never achieved.

(iv) Self-help skills are similarly delayed. Independent feeding is often not achieved by school age, and the progression from spoon to knife and fork may take some years. Toilet training is usually a long drawn out process, but a good half achieve it by school age. Personal hygiene may remain a problem eg menstrual hygiene, shaving. Children with Down Syndrome reach puberty earlier than children in the general population.

(v) Understanding of relationships, both personal and in society at large, is limited. Emotional and social maturity are rarely achieved, and the risk of exploitation is high in adult life.

(vi) Individuals with Down Syndrome tend to show the effects of ageing at a younger age than their peers. Onset of dementia of Alzheimer's disease type is common in the 40's and early 50's, with gradual loss of self-care skills.

35.10.3 Care Needs

(i) Needs will depend on the stage of development, level of ability, and presence of associated disorders, as outlined above. There is a great deal of variability in this condition, and each case will require careful consideration.

(ii) Care needs to infants without associated disabilities are usually little, if at all, greater than those of any child in early life, although sometimes the muscle tone is so poor that feeding may be a very prolonged process and, in exceptional cases, tube-feeding has to be employed.

(iii) When developmental delay becomes more apparent, usually by about a year old, needs begin to increase. Skills such as self-feeding, communication and toiletting fail to appear, creating the need for extra attention. Lack of understanding of such concepts as danger, cause and effect, and socially acceptable behaviour, coupled with a tendency to implicit trust, create the need for increased supervision.

(iv) As education proceeds, skills are taught gradually, starting with dressing. This extends in the teenage years to choosing clothes, visiting shops, managing periods, shaving (at least with help) and preparation of easy meals eg beans on toast. Although a certain amount of independence may be attained eventually, this is usually only possible within a structured environment.

(v) Night needs, in the absence of any associated disorder, should be little more than normal.

35.10.4 Mobility Considerations

(i) Mobility needs arise in young children when walking is slower than usual to develop. Most affected children are able to walk by 5 years of age, but slow development is common if a child has repeated spells of immobilisation due to illness, and especially if there have been periods of hospitalisation. The presence of a severe cardiac, respiratory, or other disorder may, of itself, give rise to mobility needs.

(ii) When physical mobility has been established, independence may eventually be achieved on simple well-known routes but not, usually, in unfamiliar surroundings.

35.10.5 Duration of Needs

Some needs existing in childhood decrease as self-care skills are learned. This is a slow process which often continues into adult life. Needs persisting beyond school leaving, however, are likely to remain.

35.10.6 Further Evidence

If additional evidence is needed, the most appropriate source will depend on what aspect of the case is under consideration. Information about associated disorders, periods of hospitalisation and other purely medical issues will be best obtained from the GP or hospital concerned. Questions about development, level of functioning, behaviour etc, would be better addressed to one of the professionals involved in community care. These may include a consultant paediatrician at a Child Development Centre, specialist health visitor, school staff, or social worker.

36. BEHAVIOUR DISORDER AND ATTENTION DEFICIT DISORDER

36.1 Contents

36.2 Behaviour Disorders - Introduction

36.2.1 Children regarded as having behaviour problems form a very broad group. Parents who experience difficulty managing a child, may describe the child as having behaviour problems: it may be the expectation of the parents, or their way of managing the child, that are inappropriate, rather than the child's behaviour. Problem behaviours are common in children: they are often trivial, and of short duration. More serious persistent problems of behaviour are likely to come to the attention of professionals: health visitors; teachers; school doctors and nurses; psychologists, child psychiatrists or paediatricians. Oppositional defiant disorder, and conduct disorder, are medically recognised categories of problem behaviour.

36.3 Clinical Description

36.3.1 Oppositional Defiant Disorder

This is a pattern of negative and defiant behaviour. The child often loses his temper; argues with adults, is defiant or non-compliant to requests or rules. The child may be irritable and easily annoyed, or deliberately annoy other people. The child is often angry and resentful.

36.3.2 Conduct Disorder

This is a repetitive and persistent pattern of behaviour in which the basic rights of others, or normally accepted rules are violated. The types of behaviour included are bullying and threatening of others; initiating physical fights; using weapons to harm others; physical cruelty to people or animals; deliberate destruction of property by fire or otherwise. It also includes significant theft, running away from home for significant periods, and truancy from school.

36.4 Causes of Behaviour Disorder

36.4.1 Childrens' behaviour problems may arise from a condition affecting the child itself, or the environment in which it grows up (ie. early family experiences, parenting), or both of these. Factors intrinsic to the child include: attention deficit disorder; organic brain disease; epilepsy; mental retardation; autism and specific learning difficulties (eg. dyslexia). Family factors include: neglect; inconsistent parenting; unstable families; violence and anti-social personalities in the parents. It can be difficult to establish the precise cause in any particular case of behaviour disorder.

36.5 Care Needs

36.5.1 Although children with behaviour problems are by definition more difficult to manage, they will not require more attention for their bodily functions than normal children (unless the behaviour problems are associated with such conditions as significant mental retardation).

36.5.2 Some of these children will show poor awareness of danger, and will not learn to take more care as a result of experience. Such children will require a greater level of vigilance from parents and carers than ordinary children. However, this is unlikely to amount to continual supervision; indeed, some children are perceived as problematic largely because they are not receiving the amount of supervision which is appropriate to their age. If behaviour problems are severe and associated with another significant disability, such as severe mental retardation, then much higher levels of care are likely to be required.

36.5.3 Children with behaviour problems are often said to be difficult to settle at night. Once settled however, the majority will sleep through the night, and would be unlikely to require regular night-time attention.

36.6 Mobility Considerations

36.6.1 Children with behaviour problems do not have difficulty walking, unless there are other associated disabilities. They should be able to get around with no greater supervision than a normal child of the same age.

36.7 Further Evidence

36.7.1 Children with severe disorders of behaviour are likely to be known to professionals in the health and education services. Reports from school will be helpful; a Statement of Special Educational Needs may be available for information, or a report from an educational psychologist should be sought. Alternatively, the health visitor, GP, clinical psychologist, child psychiatrist, or paediatrician, may be able to provide a report on the degree of the child's behavioural difficulties, and the likely cause. Because of the wide range of possible behaviour problems, it is not adequate to rely on parents alone identifying their child as having a behaviour disorder.

36.8 Attention Deficit Disorder (Attention Deficit/Hyperactivity Disorder) - Introduction

36.8.1 Attention deficit disorder is a developmental disorder. Affected children have great difficulty in directing their attention to appropriate details; they have difficulty sustaining attention in tasks or play activity; they often do not listen when spoken to, and do not follow through on instructions. Such children have difficulty organising tasks and activity, and are very distractible. In addition, they are often fidgety and restless, and even have difficulty in engaging in leisure and pleasure activities appropriately. Such children are often impulsive, and interrupting and intrusive towards others.

36.8.2 Attention deficit disorder may be associated with mental retardation and epilepsy. Its presence in children greatly increases the likelihood of behaviour disorder occurring, as such children are difficult to manage and direct appropriately. It is important to note that there are drug treatments for attention deficit disorder, which are highly effective for many children. Information as to whether a child is being treated for their disorder, and the effectiveness of the treatment, should be sought. The symptoms of attention deficit disorder usually lessen gradually, even without medication, and by their second decade such children usually have better attention and less impulsivity.

36.8.3 The diagnosis of attention deficit disorder should be made by a specialist (paediatrician, child psychiatrist, or psychologist). It is not sufficient to accept the parents' own diagnosis of their child as having attention deficit disorder. Specialists vary widely in their readiness to diagnose this disorder, with some reluctant to diagnose it at all, and others using a very low threshold indeed for diagnosis. It is the overall picture of need in the individual case, rather than the specific diagnosis which is important.

36.9 Care Needs

36.9.1 Children with attention deficit disorder may require more supervision than normal children, though if within the normal range of IQ, their extra needs

should not be marked. Night needs of children with attention deficit disorder are unlikely to be great; such children often sleep well.

36.10 Mobility Considerations

36.10.1 The overactivity, distractibility and impulsivity of these children may put them at risk from traffic when outside the home, and they may require some extra oversight, particularly in their earlier years.

36.11 Further Evidence

36.11.1 One would expect a specialist to be involved with such a child, and a report should be obtained from such a person. In addition, a report from school or nursery should provide useful information about care and mobility needs. Because of the variation of the frequency of diagnosis depending on the particular specialist involved [see para 36.8.3 above] advice from a Medical Services doctor may be helpful in clarifying whether the child is suffering from a severe physical or mental disability.

37. AUTISM AND ASPERGER'S SYNDROME

37.1 Contents **Paragraph**

37.2 Autism - Clinical Description

37.2.1 The diagnosis of autism is made on the basis of behaviour. Abnormal social interaction, absent or abnormal language and communication, and restricted stereotyped and repetitive ranges of interests and activities are central to the diagnosis. Autism has an organic basis. Genetic influences, brain disease and brain damage, may underlie autistic behaviour, though often no organic pathology can be demonstrated. Autism is a developmental disorder. Early development (up to two years) may appear normal; there may then be an arrest of development or reduced skills (particularly language). Mental retardation is present in about 75% of cases of autism. Intellectual level is important in predicting the outcome; children with higher IQ tend to do better.

37.2.2 Impaired social interaction may be so extreme that the child appears totally indifferent to the presence of other human beings. Milder abnormalities of social behaviour include inadequate understanding of social cues, with consequent inappropriate behaviour. Language and communication abnormalities range from complete absence of spoken language and its associated gestures to milder forms in which language is sparse or abnormal in its form. There is difficulty in understanding how other people feel, and in predicting the behaviour of others with whom the child comes into contact. The child's own behaviour is often rigid, (with a need to impose routines on others). There may be strong resistance to change, with tantrums and screaming if routines alter, or the child is placed in unfamiliar situations. Toilet training may be delayed, and there may be feeding difficulties.

37.2.3 The social abnormalities persist, although for many children with autism gradual improvements in social behaviour and communication may be expected throughout childhood.

37.3 Asperger's Syndrome - Clinical Description

37.3.1 This may be regarded as a mild form of autism. Most children are within the normal range of intelligence; language usually develops, and is often fluent, though used in an unusual or eccentric manner. This is described as **semantic pragmatic disorder** in which the child uses words he has heard but does not understand and which he therefore uses inappropriately. Children with Asperger's syndrome are more likely to show interest in other people than those with autism, but their social behaviour is naive and inappropriate, so they are often rejected by their peers. Rigidity and repetitiveness of behaviours are often present, with the likelihood of tantrums if routines are interrupted. Children with Asperger's syndrome are markedly clumsy, but do not usually have significant difficulty walking.

Diagnosis of these children may be missed, and initial diagnoses may be made at any time including during adult life. Adults with Asperger's syndrome may be capable of independent living, work, and may marry and raise families.

37.4 Autistic Spectrum Disorder

37.4.1 This covers the whole range of autism and Asperger's syndrome. If this term is used, it is essential to obtain additional information, as one can make no assumptions about care needs without further qualification.

37.5 Care Needs

37.5.1 Although there is no specific treatment for autism, many children do benefit from speech therapy, and parents may need to take children for therapy, and do 'homework' with them. Autistic children are likely to be delayed in toilet training, though many (depending on IQ) will eventually achieve continence. Feeding problems also occur with food fads, refusal of foods, and insistence on specific types of food. Extra time may be required to ensure that such children are appropriately fed. Generally, the help they need with bodily functions will be related to IQ.

37.5.2 Children with autism and mental retardation will require care as for a younger child, but this may be made much more difficult by the lack of communication and social responsiveness. Autistic children who are very resistant to change will be very difficult to handle in many situations. Children with autism and IQ in the normal range will still be more difficult to care for because of the communication difficulties. They may also be less responsive than normal children to parent's attempts to teach them self-care, and they may be particularly slow to learn about toileting. Children with Asperger's syndrome who have a normal IQ may not be significantly different from normal children as far as their care needs are concerned.

37.6 Mobility Considerations

37.6.1 Children with autism and Asperger's syndrome are unlikely to have significant difficulty walking. However, the more severely affected will require an adult to accompany them if out, as they are likely to put themselves at risk, eg. in relation to traffic, to strangers, and to getting lost. With some autistic children, it is impossible to use public transport, because of the child's fears and consequent resistance and tantrums. Such mobility needs may well lessen over time.

37.7 Further Evidence

37.7.1 Children diagnosed as having autism, or Asperger's syndrome would usually be under the care of the paediatrician, child psychiatrist, or psychologist. A hospital specialist's report should assist in determining the care needs of the child. Evidence about IQ is particularly helpful, and may be available from an educational psychologist, or from the Statement of Special Educational Needs, which school-age children should have. A factual report from the child's school or nursery should also be a useful source of information, both as to care and mobility needs.

38. SPEECH AND LANGUAGE DISORDERS

38.1 Contents **Paragraph**

38.2 Introduction

38.2.1 This chapter overlaps with other chapters, such as children with mental retardation [Chapter 35], normal development and disability in children [Chapter 33], behavioural problems [Chapter 36], autism [Chapter 37], cerebral palsy [Chapter 40] and deafness (39).

38.2.2 Language is the understanding of words, and speech is the way language is voiced and articulated. Communication starts at birth and develops rapidly in infancy and early childhood. There is much variety in normal children, but those whose speech and language is slower to develop, harder to understand or unusual in content are described as having speech and language delay or disorder. This may be part of a more general condition or may be a specific problem.

38.2.3 Speech and language disorders can affect a child's mental development as well as the ability to communicate and understand others. This results in difficulties with relationships, educational development, behaviour and personal growth.

38.2.4 There are many reasons for children being slow in developing language and speech. These include learning disabilities and disorders, epilepsy [Chapter 34], autism, hearing impairments, elective mutism (see below), physical abnormalities such as cleft lip and palate, and cerebral palsy. It is not uncommon for speech and language difficulties to be acquired, and in childhood frequent causes are head injury and acquired deafness. Social deprivation is also a cause of language delay or reluctance to speak. Apart from all these, there are a number of developmental disorders which occur among a significant number of children who are otherwise developing well, and for whose condition there is no apparent reason. It is those in this latter group who may be referred to as having a "specific speech and language disorder."

38.2.5 Children for whom English is a second language learn it in a few months to a year if they mix with English-speaking children and have suitable teaching. Those who have a speech or language disorder in their mother tongue find English much more difficult.

38.3 Types of Disorder

38.3.1 Some will have both speech and language disorders, thus compounding their difficulties with communication.

38.3.2 Speech Impairments

(i) **dysarthria:** a difficulty in using the muscles of articulation (the throat, mouth, tongue and larynx muscles) due to weakness, stiffness or lack of co-ordination. This is a physical difficulty which can add greatly to a child's disability.

(ii) **dyspraxia:** an inability to use the muscles of articulation because of difficulties in coordinating them to make sequences of sounds or syllables.

(iii) **elective mutism:** a willingness to speak in a limited number of situations but refusal to speak in others. A substantial minority of children with elective mutism have a history of speech delay or articulation problems. It is common for elective mutism to be associated with social anxiety, excessive sensitivity to the reactions of others and stubbornness based on fearfulness. Elective mutism most frequently appears in early childhood and occurs with approximately the same frequency in both sexes. It may respond to psychological treatment, but can be very persistent.

38.3.3 Language Impairments

(i) **developmental language delay:** a mild or severe delay in a child's development of language. Once the child's language does appear, it usually develops normally in sequence and pattern. Whilst early delay may resolve itself, it may turn out to be a long-term delay or disorder.

(ii) **developmental language disorder:** a severe delay and abnormality in the development of understood and/or used language. It is hard for children with this condition to develop their language due to its disordered nature.

(iii) **aphasia:** an absence or severe impairment of the ability to use language resulting from abnormal development of, or damage to, the brain.

38.3.4 Associated Difficulties

Behaviour problems are common in children with speech and language disability. [See also Chapter 36]. These include signs of frustration or anxiety, tantrums and, in older children, depression. Enuresis (wetting), soiling and sleep disturbances are common. Trying to gain attention by physical contact rather than by speech may be misinterpreted as aggression. Attention deficit hyperactivity disorder (hyperactivity with a very limited attention span) affects some, as do autistic tendencies (aloof or unusual social behaviour, lack of imaginative play, repetitive habits or mannerisms and difficulty in coping with anything new).

38.4 Care Needs

38.4.1 The care needs of children with speech and language disorders arise from difficulties they have with instructions or conversation, in making themselves understood, in associated behaviour problems and in relation to associated disabilities such as hearing loss, co-ordination or feeding difficulties.

38.4.2 It is more difficult for parents of children with speech and language disorder to gain the children's attention and to make themselves understood. The children may find making known their needs frustrating. Care requires patience and expert advice. In more severe cases children may use signing or symbol systems as forms of augmented communication, at least for a few years. These have to be learned by parents and other carers.

38.4.3 Most children with speech and language disorders do not have special care needs at night. There is a greater risk of enuresis and sleep disturbance in a minority.

38.5 Mobility Considerations

38.5.1 Most children with speech and language disorders have no special mobility needs. However, they may find it more difficult to understand instructions, and those who also have hyperactivity [see Chapter 36.] and a very limited attention span may behave impulsively out of doors.

38.5.2 Mobility needs may arise from associated conditions.

38.6 Duration of Needs

38.6.1 The condition of most children with speech and language disorders improves with time and increased maturity. Children whose speech has been unintelligible in pre-school years usually become intelligible by the age of seven to nine years. Spoken language disorders improve over a similar period in the majority of affected children, though many have difficulties with reading, spelling and writing.

38.6.2 Exceptionally, children may have such a persistent speech and language disability that they require continuing placement in special schools or units, for example those in which special language programmes or signing or

symbol systems are understood and used.

38.7 Further Evidence

38.7.1 Additional evidence may be sought from a child's speech and language therapist, school or community paediatrician.

39. BLINDNESS AND DEAFNESS IN CHILDREN

39.1 Contents

39.2 Introduction

39.2.1 Both sight and hearing contribute to the child's ability to communicate effectively. A child with severe visual impairment or total blindness is disabled by the inability to see written words. In addition, when moving around the child is exposed to dangers which a sighted child would not encounter. Likewise, severely deaf children are handicapped, not only by the diminished ability to hear the spoken word and so acquire language, but by the diminished ability to monitor their own speech and so formulate words which are intelligible to others. They also cannot hear sounds warning of danger.

39.3 Care Needs

39.3.1 If the child is to overcome the disability by being trained to develop effective means of communication, considerable attention must be given by others to this task. In addition a child who is severely blind or severely deaf initially requires substantially more attention and supervision throughout the day than that required by a child of the same age to protect the child from danger.

39.4 Mobility Considerations

39.4.1 The Blind Child

Outdoors in unfamiliar surroundings, the great majority of children with blindness will require guidance or supervision from another person.

39.4.2 The Deaf Child

By the time a child with long-standing profound deafness has reached puberty, he may have learned how to cope with traffic and how to get from one place to another in safety. However these abilities require good communication through spoken language which some deaf children will not have at puberty. A deaf child's ability to understand spoken language may be developmentally behind adolescents who can hear.

39.5 Duration of Need

39.5.1 The need for attention is greatest in the earlier years, but may diminish as the child matures and acquires alternative means of communication. However some deaf children will be struggling with their attempts to learn the spoken language. By puberty, the blind child may be a competent touch reader, and may have learned how to cope with traffic and how to move around in familiar surroundings without danger. However, when outdoors in unfamiliar surroundings the very great majority of blind children will require guidance or supervision. The deaf child may have acquired some degree of effective communication with those he is likely to encounter. The deaf child may also have learned how to cope with traffic.

39.5.2 Emotional and behavioural problems may arise in blind and deaf children for a variety of reasons. As the child gets older and comes to appreciate the significance of his disability, he may become frustrated and have difficulty in coming to terms with the handicap. These problems may delay progress in learning to communicate, to avoid danger and to become independent. Likewise, if in addition to blindness or deafness, there is mental or other disability, progress may be very substantially delayed.

39.5.3 The parents may sometimes fail to appreciate fully the progress the child has made towards independence. If there continues to be an established need for continued attention or supervision by day based on evidence both from home and school, these are not likely to change during the remainder of childhood.

39.6 Further Evidence

39.6.1 Assessment of the teenager's needs may also be greatly assisted by reports from teachers or specialist welfare workers particularly if there are emotional or behavioural problems. A copy of the statement of the child's educational needs, which the Education Authority is now required by law to complete for each pupil, should also provide relevant information.

39.7 Combination of Blindness and Deafness

39.7.1 Care Needs

A child who has severe impairment of both vision and hearing is unable to use one sense to compensate for loss of the other, and is unlikely to achieve independence by puberty. Needs, especially for day attention and supervision will persist beyond that age, at least until the end of childhood. Requirements for night attention or watching-over are not likely to arise by reason of blindness and deafness alone.

39.7.2 Mobility Considerations

(i) A child aged 5 years or more may satisfy the conditions for the higher rate mobility component if he is both deaf and blind, and as a result he is unable to walk to his intended destination out of doors without the assistance of another person. The degrees of disablement resulting from loss of vision and loss of hearing must amount to 100% and 80% respectively.

(ii) The degrees of disability resulting from blindness and deafness can only be assessed by experts. A Medical Services doctor may be asked to arrange for sufficient evidence to be collected to determine these issues.

(iii) Even if the degrees of disablement resulting from losses of vision and hearing do not meet the criteria for the higher rate of the mobility component of DLA, a child with substantial impairments of vision and hearing is likely to require the guidance or supervision of another person when out of doors.

40. CEREBRAL PALSIES IN CHILDREN

40.1 Contents

40.2 Introduction

40.2.1 Cerebral palsies are disorders of posture, movement and muscle tone resulting from abnormal structural development or non-progressive lesions of the immature brain, which in the majority of cases arise at, around or before birth. Birth injuries used to be a common cause, but now account for only some 10% of cases. Cerebral palsies are not specific diseases but are groups of disorders of varied causes and commonly associated with sensory defects (ie. impairments of vision, or hearing, or touch, etc), learning difficulties/mental retardation, and epilepsies. Cerebral palsies are among the most common disabling conditions of childhood.

40.2.2 The incidence of cerebral palsy is about 2 per 1000 live births. Premature babies are at increased risk. Cerebral palsies are commoner in males and a high proportion are first-born children. The predominant features of the resulting disabilities are impairments in self-care, independent mobility and social interaction, which includes communication.

40.3 Clinical Features

40.3.1 Children with cerebral palsies show stereotyped postures, with limited and/or lack of variety in their movements. The diagnosis cannot be made with confidence in the first few months for most children. There are some children who appear to have cerebral palsy at 8-12 months but later show no physical disability. The commonest presenting features in infancy include excessive mobility, apathy, unexplained seizures, and feeding difficulties

40.3.2 The disturbances of posture, movement and muscle tone can present as spasticity and rigidity of muscles which can lead to abnormal postures and deformities of limbs. Swallowing may also be affected. In **spastic quadriplegia** all four limbs are involved. **Diplegia** means that the muscle problems are much more severe in the lower limbs than in the upper extremities. **Spastic hemiplegia** accounts for about one third of children with cerebral palsy. Here one side of the body is affected and there is often impaired and defective vision. **Monoplegia** is a spastic weakness confined to one limb, and is very rare, often resolving with time. Other features may

include athetosis (involuntary movements) in limb and facial muscles with abnormal posturing of hands. Deafness may also be present. The combination of these spasmodic involuntary movements with absence of speech caused by deafness may give a false impression of severe mental retardation. Ataxia (lack of balance), especially of the trunk, may be a feature.

40.3.3 Most people with cerebral palsy have language or articulation problems (ie. difficulty in communicating), about 33% have epilepsy in childhood and at least 25% have some impairment of visual function which may be due to refractive errors in the lenses of the eye, or squints, or a defect in the part of the brain which is concerned with seeing. Behavioural problems [Chapter 36] and learning difficulties [Chapter 35] may also be encountered. As affected children grow up, deformities may appear. The most serious are scoliosis (curvature of the spine) and acquired dislocation of the hip. Persistent deformity causes difficulty in nursing and hygiene.

40.3.4 About 95% of affected children will live to adulthood. The outlook for the child with cerebral palsy depends largely on the severity of any associated intellectual and learning disabilities. Good adjustment may be made to fairly severe muscle problems as long as intellectual capacity is good. The response of the family to the situation and the availability of adequate educational and therapeutic facilities are of great importance.

40.4 Care Needs and Mobility Considerations

40.4.1 Because of the physical disabilities and learning disabilities/mental retardation which may be present in varying combinations and degrees (and, possibly, coexisting with other complications and associated disabilities - see para 40.3) an extremely complex picture may present both of the total disablement and the aggregated needs arising from it. Each case will require careful and individual assessment. Reference may also be made to chapters dealing with related conditions [see para - 40.1].

40.4.2 About 75% of children with cerebral palsy eventually walk. However the manner in which progress is made, and the gait adopted, may, among other factors result in a substantial limitation of walking abilities. Children who have multiple disabilities and/or have severe spasticity affecting all four limbs may never be able to walk.

40.5 Further Evidence

40.5.1 Parents of children with cerebral palsies are usually greatly involved in the programmes of effective family support and should thus be able to provide the

great majority of information required in determining care and mobility needs. If required, further evidence may be sought from staff at a Child Development Centre, the GP, a developmental paediatrician, or a paediatric neurologist.

41. CEREBRAL PALSIES IN ADULTS

41.1 Contents **Paragraph**

Related conditions considered in other chapters

41.2 Introduction

41.2.1 Cerebral palsies are disorders of posture, movement and muscle tone resulting from abnormal structural development or non-progressive lesions of the immature brain, which in the majority of cases arise at, around or before birth. Cerebral palsies are not specific diseases but are groups of disorders of varied causes and commonly associated with sensory defects (ie. impairments of vision, or hearing, or touch, etc), learning difficulties/mental retardation, and epilepsies. Cerebral palsies affect one adult in 400.

41.2.2 Cerebral palsies arise from abnormalities of brain development before birth or from damage to the brain in the womb, during birth or in infancy. The predominant features of the resulting disability are impairments in self-care, independent mobility and social interaction, which includes communication. In late middle age there is an increased risk of memory loss, dementia and osteoarthritis.

41.3 Clinical Features

41.3.1 Adults with cerebral palsies may show laborious movements due to spasticity (stiffness of muscles of the limbs). If this affects one side of the body it is called a **hemiplegia,** if it affects all 4 limbs it is called a **quadriplegia,** if it affects the mouth muscles it is called a **bulbar palsy.** Others show involuntary movements of a writhing (athetoid) and/or jerking nature (chorea). If there is unsteadiness or lack of balance this is known as **ataxic cerebral palsy.** Some people have mixed forms of cerebral palsy - eg ataxia and spasticity. Skeletal deformities are common eg. curvature of the spine (scoliosis), dislocation or restricted mobility of the hip(s), deformities of the ankle or foot requiring use of appliances eg. calipers or special footwear.

41.3.2 About a third of adults with cerebral palsies have associated learning disability in the moderate to severe range. A further third have patchy or specific

learning disabilities (eg in literacy, numeracy or perception). The remainder are of normal intellectual ability or above average ability. In some the severity of the physical disability (eg athetosis) may bear little relation to intelligence.

41.3.3 Communication difficulties are common in adults with cerebral palsies: reasons include specific difficulties in comprehension or expressive language, impaired speech articulation, and associated hearing loss, learning disability or autism. Augmented communication with symbol systems, word processor or speech synthesizer may be used. Visual impairments are much commoner than in the general population. Refractive error may be correctable by glasses. There may be retinal disorder in the eye, either from developmental disorders, damage by viral infection in the womb, cataracts or cortical visual impairment from developmental abnormality or damage to the brain.

41.3.4 About 10 per cent of adults with cerebral palsies have epilepsy, often severe. [See Chapter 14].

41.3.5 Life expectancy for adults with cerebral palsies depends on the type, severity and associated disabilities as well as the quality of care. It ranges from about 30 years for those with rigidity or severe spasticity associated with epilepsy and feeding difficulties, to 60-70 years for those with moderate cerebral palsy, and to a normal life expectancy for those with mild disability and no associated impairments.

41.4 Care Needs

41.4.1 About one third of adults with cerebral palsies may be expected to be independent and self-supporting with suitable education and support in childhood adolescence and early adult life. More severely affected people may require help with dressing and undressing, and with personal hygiene. Help may also be needed with cutting, mashing or blending food. Those most severely affected may be unable to feed themselves without help from another person.

41.5 Mobility Considerations

41.5.1 About 75% of adults with cerebral palsies can walk in the home and for varying distances out of doors. The manner in which progress is made, the gait adopted and the effort required may among other factors result in substantial limitations of walking abilities. Aids such as a walking stick, elbow crutches or a walking frame may be required, with a wheelchair for longer distances.

41.6 Further Evidence

41.6.1 Families of adults with cerebral palsies are often closely involved in their care and support and can provide much of the information required in determining

care and mobility needs. Further evidence may be sought from the social worker, a therapist, the GP or a consultant in rehabilitation medicine who has been involved in the management of the disabled person.

42. DIABETES MELLITUS IN CHILDREN

42.1 Contents

42.2 Introduction

42.2.1 Diabetes mellitus results from the failure of a gland (the pancreas) to produce sufficient amounts of a hormone (insulin) which enables the body to use sugar. It can develop at any age but the earlier this is the more serious its effects are likely to be. It occurs in 2 per 1000 children with peak presentations at around 7 years and 12 years of age. Its onset is usually sudden, and causes profound upset for the child and family, not least because of the implications for the child's future health and welfare. This type of diabetes mellitus always needs treatment with insulin injections. This is called insulin-dependent diabetes.

42.3 General

42.3.1 The use and handling of sugar (present in foods) is essential for the health and normal functioning of all the systems of the body. The use of sugar by the body also varies in different situations, such as when exercise is undertaken, or when an infection is present. In healthy children these variations are dealt with as a matter of normal functioning of the body, but in those with insulin-dependent diabetes a careful balance of sugar and insulin can only be achieved by various combinations of control of diet, injections of insulin, and modification of bodily activity and lifestyle.

42.3.2 Management of the condition involves the provision of a prescribed diet, the injection of insulin and the testing of blood and urine to monitor sugar levels, all of which need to be done accurately and at the appropriate times. It is extremely important to maintain the best possible control of blood sugar levels as this will reduce the development of complications in later life. Management also involves the prevention, recognition and treatment of primary complications such as low blood sugar (hypoglycaemia), accumulation of toxic substances in the blood because of the inability to utilise blood sugar (ketoacidosis), and infections.

42.3.3 Blood tests are usually performed about twice a day. If the child has an

infection, or the blood sugar is high or unstable, or there is unaccustomed physical activity, they will be done more often and the urine may also be tested. Additional injections, or changes in the dosages of insulin may also be needed in these circumstances. Difficulty may be encountered, in some cases, in establishing an ideal routine and the frequency and type of monitoring may be tailored to the individual child.

42.4 Hypoglycaemia

42.4.1 Hypoglycaemia is a condition in which the concentration of sugar in the blood is lower than normal. It is, together with ketoacidosis [see para 42.5], one of the primary complications of diabetes, and potentially dangerous, requiring prompt recognition and treatment to avoid potentially life-threatening situations. It may be caused by such things as too much insulin being given, not enough food being taken, delay in taking a meal, food being vomited, too much exercise or indeed anything else which affects the balance of sugar to insulin in favour of an excess of insulin. It is not uncommon in children with diabetes, particularly in younger children who have unpredictable levels of activity, when blood sugar content may vary greatly. In such children satisfactory control may be difficult to achieve.

42.4.2 The warning symptoms of hypoglycaemia are very variable, and may include hunger pains, sweating, trembling, blurred vision, poor concentration, irritability, bad temper and confusion. It may occur suddenly and unpredictably, and young children may not recognise the significance of the warning symptoms in the way that older children and adults are likely to. However, even some older children or adults may have difficulty in recognising its onset.

42.5 Ketoacidosis

42.5.1 Ketones are toxic substances which accumulate in the blood when the blood sugar levels are too high (hyperglycaemia), causing a condition called ketoacidosis. This is the opposite of hypoglycaemia [see para. 42.4], and is the other primary complication of diabetes. It is extremely dangerous, also requiring prompt recognition and treatment to avoid life threatening situations. It is caused frequently by the presence of an infection, which increases the need for insulin, but also by such things as too little insulin being given, too much food being taken, blood sugar being used at a low rate, or anything else which affects the balance of sugar to insulin in favour of an excess of sugar. Like hypoglycaemia, it is not uncommon in children with diabetes, as infections are common in childhood, and particularly in younger children whose unpredictable levels of activity lead to great variation in blood sugar content. This may make it difficult to achieve satisfactory control of their condition.

42.5.2 Ketoacidosis may occur unpredictably and its onset may be rapid, over a period of a few hours, but not so rapid as is often the case with hypoglycaemia. Warning symptoms and signs are variable, but may include fatigue, thirst, abdominal discomfort and vomiting. Young children may not

recognise the significance of the warning symptoms in the way that older children and adults are likely to. Parents of children with diabetes have almost always been made aware of these warning symptoms and signs by the health care professionals involved with the management of the affected child.

42.6 Care Needs

42.6.1 The prescribed diet has to be measured and its consumption ensured by an adult. Food must be taken at regular intervals, and meals cannot be missed or delayed. A degree of vigilance may also be required to ensure that the child adheres to the diet and does not eat extra foods that raise the blood sugar level, outside the regular meal plan. The correct dose of insulin is critical and must be measured accurately. It is usually given twice during the day, but may be needed more often. The testing of blood or urine with a kit is required usually twice, and often several times, in the day. Sometimes this is also required during the night, and particularly in young children whose sleep requirement leads to a long overnight fast. This poses a problem in terms of getting good control without running the risk of overnight hypoglycaemia.

42.6.2 Because younger children will have neither the skill nor the understanding to administer insulin, test blood or urine, or manage their own diet, these tasks have to be undertaken by an adult. Because they are seldom able to recognise the warning signs of hypoglycaemia or ketoacidosis they need an adult to be on the lookout for these and to take appropriate action to prevent the development of a life-threatening situation. Until the child reaches an age when these various tasks can be safely and reliably carried out without assistance from an adult the care needs by day are many and may take up a considerable amount of time.

42.6.3 An important "care need" is the judgement as to when an adjustment needs to be made to treatment, either independently by the child and family, or with telephone advice from the specialist nurse or doctor, or by attending the doctor in general practice or hospital. Such a judgement is often difficult for carers to make, but is a very important one. The child or adolescent may well not be able to make that decision for themselves.

42.6.4 At night the needs are not so great except where there is regular overnight hypoglycaemia. For older children, night alarms can be set to go off through the night waking them, to check their blood sugar level and eat something, if necessary, to prevent hypoglycaemia. For younger children with regular overnight hypoglycaemia the use of night alarms may be impractical, and it may be reasonable for an adult to check on the child at intervals throughout the night.

42.7 Mobility Considerations

42.7.1 Children with diabetes are very unlikely to have any mobility needs as a result of their condition.

42.8 Duration of Needs

42.8.1 The age at which a child attains reliable independence from adult assistance is variable, as the management of this condition is complex. Blood sugar levels are rarely static, their constant fluctuation depending on factors such as food intake, exercise, temperature, general health, emotional state and others, not yet well understood.

42.8.2 Good management depends on teamwork between parents and children. As they grow older and develop understanding of the condition, children begin to take a more active part in its management. When they become more independent, often in early adolescence, many children may be able to give themselves the correct dose of insulin, test blood and urine and avoid inappropriate foods, but others have problems coping with the complexities of their condition and may need help for much longer. If supervision or assistance is still required with the administration of insulin, this may be for no more than a few minutes to check the dose is correct each time an injection is given. By the time this stage is reached, they may also be better able to recognise the warning symptoms of hypoglycaemia and take appropriate action.

42.8.3 These considerations would not normally apply to a child who has been first diagnosed as having diabetes around the time of puberty or in early adolescence. In such a case the needs will be similar to those of a younger child, and are likely to continue for about two years before they may be able to deal with their diabetes unaided.

42.8.4 In some cases, even though children in their teens have had diabetes for some time, the evidence may suggest that control has still not been properly achieved, because frequent episodes of hypoglycaemia occur, or they have suffered from ketoacidosis on more than one occasion since being diagnosed, or because their diabetes is said to be "unstable". When hypoglycaemia attacks or episodes of ketoacidosis continue to occur by day and/or by night, the need for supervision and/or watching over is likely to continue, even in those who have reached the age at which independence would normally be expected. The response of these episodes to treatment varies in each individual case but the likelihood is that the condition will stabilise after a period (commonly not more than two years) of careful monitoring, with adjustment of treatment and day-to-day activities.

42.8.5 With the onset of puberty, control of diabetes may become difficult for a time, even if it has previously been stable. Also, the child may become resentful about the condition and less co-operative in its management. In these circumstances, the need for supervision may continue for a further year or two.

42.8.6 In some affected individuals control may fluctuate for inexplicable reasons, periods of stability up to six months at a time being followed by similar periods of instability. Such a pattern developing in childhood is likely to persist to

young adulthood.

42.9 Further Evidence

42.9.1 If information already available is inadequate for assessing the child's needs, then a factual report from the hospital may provide extra detail. This will be especially helpful if completed by the diabetic specialist nurse, who is likely to be visiting the home and providing the first line of help in case of difficulty.

42.9.2 Some parents deal effectively with hypoglycaemia without help, and are given kits to use when attacks are too severe for the child to be able to swallow a sweet or sugary drink. A glucose gel may be squeezed into the space between the teeth and the inside of the cheek, where it is rapidly absorbed, or an injection of a substance called Glucagon may be necessary to restore the blood sugar level. A report from the GP or hospital on the frequency of prescription of either of these substances may help to determine their incidence. In some instances, especially where control appears poor, a consultant report may be helpful in establishing the nature, frequency and severity of hypoglycaemic attacks.

43. METABOLIC DISORDERS IN CHILDREN

43.1 Contents: **Paragraph**

43.2 Introduction

43.2.1 Metabolic disorders (inborn errors of metabolism) are due to inherited single enzyme defects. The loss of normal enzyme activity causes a block in the metabolic pathway which in turn may produce a characteristic picture of disability. About 200 different examples are known. Some of these have no disabling effects of importance, others cause varying degrees of disability, and some may be incompatible with life. In most cases, the change in the structure of the enzyme either reduces or abolishes its effects. In other cases no enzyme at all may be produced.

43.2.2 These conditions are rare but in many instances cause severe disability, particularly severe learning disability, so they are important because of the care and mobility needs that can arise. They have a variety of effects, depending on the metabolic pathway affected, for example, haemophilia (absence of a blood clotting factor), albinism (absence of skin pigment and impaired vision) and phenylketonuria (inability to metabolise the amino acid phenylalanine which can result in brain damage).

43.2.3 The cause of these conditions cannot be corrected yet so treatment is aimed at their effects. For example, haemophilia is treated by replacing the missing clotting factor; albinism is helped by avoiding the damaging effects of bright sunlight; the damaging effects of phenylketonuria are prevented by restricting the amount of phenylalanine in the diet.

43.3 General

43.3.1 This section will deal with the care and mobility needs that arise from those conditions that require dietary restrictions as these form quite a large group with similar effects and needs. Other conditions such as haemophilia are dealt with separately [Chapter 47].

43.3.2 The classic example of an inborn error of metabolism treated by dietary

restriction is phenylketonuria (PKU). Children with this cannot break down the amino acid phenylalanine. Testing of all newborn babies for this condition and dietary restriction for those found to be affected means that now the vast majority grow up without any intellectual impairment at all. For many it is possible to relax the diet during adolescence. Women of childbearing age who wish to become pregnant will need to pay particular attention to their diet. For some with PKU and for those suffering from other disorders, dietary restriction is not so successful. The most serious effects of these conditions are on the developing brain, leading to learning disability, behavioural disturbances and epileptic fits.

43.4 Care Needs

43.4.1 Those with PKU who have been successfully treated from birth will develop normally, both physically and intellectually. Those treated less successfully will have the same care needs as any other child with severe learning disability [Chapter 35], behavioural disturbances [Chapter 36] or fits [Chapter 34].

43.5 Mobility Considerations

43.5.1 Children who have been treated for the condition since birth will develop normally and have no problems with walking. Children whose untreated disease has led to learning disability may have mobility needs as already described in Chapter 35.

43.6 Duration of Need

43.6.1 The effects of these conditions are irreversible so where there are care and mobility needs these will be lifelong.

43.7 Further Evidence

43.7.1 Many children will be attending a Child Assessment Unit which would be able to provide a report on their overall development.

44. CYSTIC FIBROSIS

44.1 Contents **Paragraph**

44.2 Introduction

44.2.1 Cystic fibrosis is an inherited condition due to an abnormal gene. The clinical features are due to an alteration in the mucus produced in the cells lining the lungs and in many organs which secrete mucus, notably the pancreas.

44.2.2 In cystic fibrosis there is increased salt in sweat, the secretions from the lining of the airways in the lungs are more viscous (stickier) and there is pancreatic insufficiency. Pancreatic insufficiency causes decreased secretion of certain enzymes which digest food in the gut, and leads to malabsorption of food with the passage of frequent, loose, offensive stools. The thick secretions in the airways result in an increase in recurrent lung infections, which eventually lead to lung tissue destruction. Late complications include diabetes and liver damage.

44.2.3 The prognosis has consistently improved; 90% of children with cystic fibrosis now survive well in to their teens and many well into young adulthood. This advance is due to improved treatment of bronchial infections and better maintenance of nutrition, together with meticulous attention to measures such as chest physiotherapy. Heart-lung transplantation is increasingly being undertaken with consequent limitation in the severity of disabilities.

44.2.4 At any particular time the condition of a child with cystic fibrosis can be classified as:

(i) Normal clinically - although the child has the disease, symptoms are controlled by regular treatment, and growth and development are normal.

(ii) Mild - the child has symptoms referable to the chest and/or digestive system, but is free from sputum (mucus from the lungs sometimes containing blood or pus). Gaining weight and enjoying normal activities are achieved on regular treatment.

(iii) Moderate - the child has increasing sputum, problems with the digestive system, limitation of general activities and variable impairment of growth and

development.

(iv) Severe - the child has repeated flare ups of chest infection, persistent cough with copious sputum, weight loss, shortness of breath and greatly reduced exercise tolerance. A proportion have additional complications.

44.2.5 Most adults with cystic fibrosis have serious respiratory disease. Respiratory failure is the most frequent cause of death. Recurrent chest infections result in breathlessness and copious, thick sputum, at times blood stained. As the disease progresses, the chest infections become more frequent and there may be wheezing, finger clubbing and blue discolouration of the skin due to poorly oxygenated blood (cyanosis).

44.2.6 Treatment includes physiotherapy (mainly postural drainage) at least twice a day, antibiotics (both oral nebulised - in the form of a spray - and intermittent courses intravenously), inhaled bronchodilators and a high energy and protein diet with supplements of pancreatic enzymes and vitamins. It has long been recognised that close attention to treatment has a significant effect on prognosis. However, it is now apparent that prognosis can be further improved when the management is supervised by specialist centres which give very intensive therapy in the form of physiotherapy, intermittent intravenous antibiotics, nebulised bronchodilators and nutritional support.

44.3 Care Needs

44.3.1 The needs of those with cystic fibrosis are dependent on the severity of the disease, the nature of any infection present and their age . History and clinical findings, including growth, will help assess these factors.

44.3.2 It is possible to maintain some children in a symptom free and generally healthy state by use of physiotherapy and other measures outlined in 44.2.6. Precisely the same measures are used to treat children during acute infections, although they may be given more intensively, especially the physiotherapy. The need for the attention to keep a child in a healthy state is just as necessary as that required during acute infections. It is therefore important to note that children may only appear healthy because of the amount of attention being given, and that without this attention there would be a deterioration in the condition.

44.3.3 The amount of attention required by a child who receives physiotherapy twice daily, maintains normal height and weight, remains symptom free and engages in normal activities is likely to take at least 30 minutes twice a day. Some children are only maintained in this state with additional physiotherapy together with the frequent use of nebulised bronchodilators and antibiotics,

with which they will require help. Nebulised antibiotics are usually given twice a day and will require assistance from a parent or carer until the child is mature enough and sufficiently independent to handle these matters alone. Some children may not be receiving the amount of attention their condition requires. A child who is not thriving, has repeated chest infections and restricted activity, despite receiving twice daily physiotherapy, in fact actually needs a programme of more intensive and frequent attention throughout the day.

44.3.4 There is an increasing trend towards the use of intermittent courses of intravenous antibiotics at home. During these courses, which usually last several days, administration of the antibiotics will be about three or four times throughout the day and will need to be given by an adult. Although these courses are given intermittently, they will nevertheless affect the overall amount of attention needed by the child over a period of time.

44.3.5 Adults and young adults, unless they are in a very poor condition, will be able to carry out postural drainage and administer bronchodilator drugs/antibiotics unaided. The age at which this level of independence is achieved will depend on clinical condition and maturity. It is unlikely that a child would be able to manage treatment without assistance before puberty. Many older children also require assistance with the physiotherapy from time to time, especially when unwell.

44.3.6 Most people with all but the milder forms of cystic fibrosis require the support of a carer at home for the intensive and time consuming regimes that are so necessary. In mild or moderate cases it is not usual for attention to be required at night. However, if the general condition is poor, a session of physiotherapy may be required at night. Likewise, physiotherapy at night may be required during periods of acute infection. In these circumstances, sleep may be disturbed by distressing coughing or shortness of breath, and attention in connection with these may be needed.

44.4 Mobility Considerations

44.4.1 Cystic fibrosis in itself does not give rise to a need for assistance when walking out of doors. However, it can give rise to walking problems because of shortness of breath, particularly when it has reached the stage of being severe. The effects of cystic fibrosis on a person's mobility will need to be assessed on the evidence available in an individual case.

44.5 Heart/Lung Transplantation

44.5.1 In recent years, an increasing number of heart/lung transplants have been taking place. A significant number of these have been in patients suffering from cystic fibrosis. In uncomplicated cases, patients are discharged from hospital four to six weeks after surgery. Post operative patients are required to follow a

complicated and closely monitored drug regime. In addition to this, the temperature has to be recorded twice daily and a daily record kept of the weight and certain measures of lung function. Consequently, it is to be expected that such people will continue to need a considerable amount of attention by day for a further year, although this time span will vary according to the circumstances of the individual case. At that time, continuing attention needs will depend on whether the transplant has been a success and on the particular circumstances of the case.

44.6 Duration of Needs

44.6.1 Once attention needs are established, in the absence of a heart/lung transplantation, they are likely to continue indefinitely.

44.7 Further Evidence

44.7.1 A factual report from the relevant hospital is likely to be of help in determining the history, clinical findings, height, weight, treatment and response to it and other factors which would determine the amount of treatment and attention required.

45. ASTHMA IN CHILDREN

45.1 Contents

45.2 Clinical Features and Description

45.2.1 Bronchial asthma is a disease of the chest characterised by episodes of breathlessness accompanied by wheezing (noisy breathing, especially when breathing out) and cough. It is caused by a narrowing of the airways carrying air to and from the air sacs in the lungs. These airways are called bronchioles. In asthma, the resistance to the flow of air through these bronchioles is variable which in turn leads to variable symptoms. Asthma therefore tends to occur in acute attacks with complete or relative normality in between, although a small number of children with severe asthma may have persisting symptoms

45.2.2 In asthma there is an increased responsiveness (hyper-reactivity) of the bronchioles to various stimuli such as viral infections, allergens (eg the house-dust mite), pets, exercise and changes in air temperature. The reaction of the over-responsive airway is inflammation, swelling and thickening of the walls of the bronchioles, which may be associated with excessive production of thick, sticky mucus; and contraction of the muscle tissue of the bronchi themselves. All this causes diffuse narrowing of the airways and obstruction to airflow.

45.2.3 Asthma usually begins in childhood but may develop at any age. During an attack the affected child coughs, wheezes and becomes breathless and may become distressed. The symptoms vary from day to day and during sleep. This variability is due to the changes in the size of the airways and the production of excessive mucus. The narrowed airways can revert to normal spontaneously, following removal of one of the stimuli mentioned above, or as a result of treatment with drugs which either dilate the bronchioles or diminish the inflammatory response. Some children with mild asthma may not experience such attacks of breathlessness, but instead parents notice that they have a persistent cough.

45.2.4 Not all attacks of wheeziness are due to asthma. In many children they are associated with a minor infection such as a cold, and the child will be well and free from symptoms for many months at a time without the need for regular

treatment. Approximately 1 in 7 children between the ages of 2 and 15 years have symptoms of asthma requiring some form of regular treatment. In the majority of children, attacks become less frequent and less severe as the child gets older. In a small number of children the disease may be difficult to manage: such children are usually cared for at specialist hospital clinics.

45.3 Care Needs

45.3.1 Assistance with Treatment

(i) All children with recurrent wheeziness will, at some time or other, be treated with inhaled drugs. Two types of drug may be used: relievers (bronchodilators) and preventers (anti-inflammatories). Bronchodilators relax the muscles in the airways leading to the lungs, whilst anti-inflammatory drugs (usually steroids, but sometimes sodium cromoglycate) reduce the inflammation and hence the amount of sticky mucus in the bronchi. In children with only mild and infrequent asthma, an inhaled bronchodilator may only be needed during attacks and then it may be required up to four times a day. In those with rather more frequent attacks, it may be necessary for the child to take inhaled anti-inflammatory drugs twice daily on a regular basis. These children will also need to have bronchodilator treatments during acute attacks.

In those whose asthma is rather more severe, the regular inhalation of both bronchodilators and steroids may be required. In the most severely affected children, courses of steroid tablets may be required during particularly bad attacks. Courses of antibiotics are rarely necessary since most of the infections which give rise to wheeziness are due to viruses.

(ii) The needs of the child with asthma vary according to the child's age, the severity of the condition, and the frequency at which inhaled medication needs to be taken. A variety of devices are available to make the process of inhaling the required dose as easy and as effective as possible. Below the age of five, it is likely that most children will require help with treatment. Over the age of eight it is to be expected that the child will have become proficient at managing the technicalities of taking the correct dose of inhaled medication. Between these ages, the needs will depend on the circumstances of the case. For example, the need for help is likely to persist longer if a mask needs to be used in conjunction with the inhalation device.

(iii) Until relatively recently many young children used to receive their inhaled drugs by means of a nebuliser. This is a special machine which produces a fine spray of a solution of the drug, which is then inhaled through a mask. Most such children require help to use a nebuliser. With recent developments in the design of inhalation devices, almost all children, regardless of age or severity of asthma, can receive the appropriate dosage without the use of a nebuliser.

(iv) In order to evaluate response to treatment, and detect any warning of deterioration, children aged 6 or older are now instructed in the use of a portable mini peak flow meter into which they blow hard after taking a deep breath in. This gives an indirect measure of the degree of obstruction in the airways. Measurements are usually done in the morning and at bedtime. Children under about 8 years of age cannot be expected to carry this out regularly and reliably without assistance from an adult. The attention required is likely to take a significant amount of time. Older children should be able to use the mini peak flow meter unassisted. When the child is symptom free, regular checks by an adult that this is being done properly may be required only once or twice a month.

45.3.2 Variability

The time devoted to treatment administration and gauging response to it will depend on the severity of the disorder and on the frequency with which episodes of increased wheeziness occur. During the early years following diagnosis the child with established moderate to severe disease is likely to improve with modern treatment; periods of disability causing extensive attention needs will generally become shorter in duration and less frequent.

45.3.3 Attention to Bodily Functions

A child with infrequent episodes of wheezing, or whose wheeziness is well controlled by regular treatment with anti-inflammatory drugs should be able to pursue all the normal activities expected of a child of the same age. During acute attacks of wheezing breathlessness, the child's physical activity is limited and attention substantially in excess of that normally given to a child of the same age may be needed by day or at night. However in all but the most severely affected children a series of acute attacks is unlikely to last more than a few weeks.

45.3.4 Supervision/Watching-Over Needs

Supervision will not usually be required for most of the time during the day except in young children suffering acute attacks. Similarly watching-over at night, though frequently undertaken by anxious parents, is not really necessary for the very great majority of asthmatic children, Exceptions will be the occurrence of acute attacks. Because of the increased awareness of the potential dangers of poorly managed asthma in children, acute attacks of wheezing breathlessness which do not respond to therapy necessitate in-patient management. It would be most unusual for there to be no history of hospital

admissions in an asthmatic child in whom frequent severe attacks are said to occur by day and night.

45.4 Mobility Considerations

45.4.1 Most acute attacks of wheezing and breathlessness will occur in children aged under 5 years. Acute attacks which are treated appropriately are unlikely to last for more than 12-24 hours at a time: during this short period the child's ability to walk will be restricted, but will then recover as the attack resolves.

45.5 Further Evidence

45.5.1 A factual report from the GP, and the school in school age children, may greatly assist in determining the severity and frequency of attacks and whether they occur by day or night, or both. When there is a history of frequent hospital admissions a factual report from the hospital may be useful in documenting the severity of the condition and its response to treatment. A hospital report may also help to clarify the situation where it is claimed that the child requires nebuliser treatment.

46. ARTHRITIS AND MUSCULO-SKELETAL CONDITIONS IN CHILDREN

46.1 Contents **Paragraph**

46.2 Trauma

46.2.1 Trauma including fractures of bones and head injury is not uncommon in childhood. It may give rise to the need for increased attention (eg. when the child is in a plaster cast or receiving intensive physiotherapy at home). The period of increased attention is usually limited and, depending on the condition, is unlikely to last for more than three months. In those cases in which considerable attention needs persist because of the nature and severity of the fractures and resulting disability it is unlikely to be for longer than one year.

46.3 Arthritis

46.3.1 Juvenile chronic arthritis (Still's disease) is the most common form of arthritis in children. Pain, swelling and limitation of movements of affected joints are cardinal features. The number, site and degree of involvement of affected joints will determine the extent of disability and the needs it gives rise to. When the condition is in the acute stage the majority of cases will need extra attention. As the condition remits the attention may well cease to be needed. Once attention needs have become established, they will normally remain unchanged for about two years.

46.4 Congenital Dislocation of the Hip

46.4.1 Congenital dislocation of the hip is usually diagnosed, and treatment commenced, within the first year of life. Its management may be protracted, particularly if the diagnosis is delayed beyond early infancy, requiring more than one operation, each followed by periods of immobility and/or splinting of the hip. Except for children aged 1 year or less, extra attention over and above that of a healthy child will normally be required during the day. The periods of immobility and/or splinting vary between 1 and 12 months, interspersed with hospital admissions for adjustment of splints, replacement of casts, etc. Night attention is usually infrequent.

46.5 Perthes' Disease

46.5.1 This is a disease of the hip which affects children between the ages of 2 and 12 years. Most (80%) of the affected children are boys. Usually only one hip is affected in this condition. The initial treatment involves immobilization and traction (ie pulling on the leg with weights) of the painful hip. This does not usually last longer than a week. Thereafter the child is commonly fitted with a non-weight-bearing caliper or brace which protects the affected hip. The child fitted with such an appliance should be able to live a near normal life both at school and at home. The child will likely require assistance during the day with putting on and taking off the caliper; but this is unlikely to exceed a few minutes.

46.6 Spina Bifida

46.6.1 Clinical Description

(i) Spina bifida is a developmental abnormality. The neural tube (ie. that part of the developing baby which will give rise to the spine) fails to unite leaving a gap over which the skin is defective. In the severest form the baby is born with a protruding sac at the base of its spine containing either cerebrospinal fluid (meningocoele) or cerebrospinal fluid and nerve tissue (meningomyelocoele).

(ii) In this severe form the disablement includes paralysis of the lower limbs, with or without spasticity, and sensory loss which exposes the child to risk of damage to the skin and lack of control of bowel and bladder. The condition is often, though not invariably, associated with hydrocephalus (enlarged head due to increased content of cerebrospinal fluid) and with mental retardation.

(iii) There is also a very mild form of the condition called spina bifida occulta. Here there is only a minor defect in the spine in the low back region which is covered-over as normal with body tissues and skin. In general spina bifida occulta is an isolated, insignificant finding, but less commonly it can be associated with all the problems and complications accompanying the classic, open spina bifida.

46.6.2 Care Needs

In the severe forms of spina bifida substantial extra attention is required to care for the skin, prevent infection, attend to the bladder and bowel and train such functions as can be utilised to compensate for the disability. These needs will be required at night as well as during the day, and are unlikely to change until the child is at least 8 years of age - but will vary in individual cases depending on the severity of the lesion, any associated complications, and the needs posed by them.

46.6.3 Duration of Care Needs

(i) Some children with paralysis of the lower limbs may have been trained to

transfer to and from and to operate a wheelchair and to manage urinary apparatus, thus remaining clean and dry for most of the day. Despite this, the severity of the disablement usually requires a child to be supervised in these activities for most of the time. At night the needs posed by the disabilities are unlikely to require attention and/or watching-over, except during limited periods which follow corrective surgery or troublesome urinary infection. Some children with severe spina bifida will need turning at night to avoid pressure sores.

(ii) In the absence of any associated mental retardation, a child may have achieved a degree of independence by the age of 16 years which may very substantially reduce the requirements for attention and/or supervision. At this age the needs are likely to be determined by similar factors to those described in the Chapter on spinal injury and paraplegia [Chapter 18].

46.6.4 Mobility Considerations

Children with total paralysis of the legs are unable to walk. Many affected children without total paralysis of the legs are nonetheless severely restricted in their walking abilities because of weakness in leg muscles. Walking problems which are present at 5 years of age are likely to persist into adult life.

46.7 Muscular Dystrophy

46.7.1 Introduction

There are several different types of muscular dystrophy, most of which are rare. All are progressive, hereditary disorders, in which muscle fibres degenerate and are replaced by fibrous tissue and fat, resulting in gradually increasing weakness. Only those muscular dystrophies most commonly encountered will be described in detail. Their effects depend on the muscles involved and on the rate of progress of the disease.

46.7.2 Duchenne Muscular Dystrophy

(i) This is the commonest and most severe form of muscular dystrophy. In about two-thirds of affected individuals the condition is inherited through the mother, who is a carrier. In the remainder the condition is a result of a change in genetic structure, (mutation) in the egg (ovum). Only boys are affected by the disease though a few female carriers show some of the symptoms.

(ii) The condition usually becomes apparent between one and four years old, with delay in walking, a clumsy gait, inability to run properly, frequent falls and difficulty managing stairs. Learning disability is a common accompaniment, but is usually mild to moderate. [See Chapter 35].

(iii) Weakness of the leg and hip muscles gradually increases, and walking becomes

more difficult, despite the use of aids, until a wheelchair is necessary. This stage is usually reached in early adolescence. Slowly the arms become weaker, as do the muscles of the trunk, which may require a brace. Eventual involvement of chest and even heart muscle leads to recurrent chest infections, heart failure, and death, which may occur in the late teens or early twenties.

46.7.3 Becker Type

This is a variant of Duchenne, again affecting only boys. It is milder in form and later in onset, appearing usually from late childhood to early twenties. The pattern of weakness is somewhat similar but much slower in its progression so that often the affected person lives well into the thirties or forties and sometimes longer. Walking may be possible into the thirties, or even to middle age. Heart muscle is not involved, and many people, though disabled, have a normal life span.

46.7.4 Limb Girdle Dystrophy

This is similar to Becker in patterns and severity, but affects both sexes. It usually appears in the second decade of life, often in adolescence, but sometimes later, and occasionally not until middle life. Weakness may begin in the muscles of either the hips or the shoulders, but eventually both groups are involved. The disease progresses more quickly when the legs are affected first, but most people are severely disabled within twenty years of onset, and many may die early.

46.7.5 Facioscapulohumeral Dystrophy

This is generally a milder disorder than those already mentioned, and affects both sexes. Onset may be at any age from childhood to adult life, but comes on most commonly during adolescence. The muscles of the face and shoulders are most affected, causing increasing difficulty in lifting the arms, weakness of eye closure, lack of facial expression and poor pronunciation with nasal speech. Progress varies and so does the degree of disability, but most people with this form of muscular dystrophy remain active.

46.7.6 Myotonic Dystrophy

(i) This differs from other forms in being a multi-system disorder. The muscular problem may be accompanied by others involving the eyes, heart, lungs, hormone and immune systems, and the brain. As well as weakness, there is difficulty in relaxing muscles after voluntary effort.

(ii) It affects both sexes and is commonly found in adults, developing between the ages of twenty and fifty, though it may occasionally arise in childhood or even

at birth (in children of affected women) when it tends to be very severe and associated with learning disabilities. The first symptoms are usually weakness of the hands and difficulty with walking. Poor vision, weight loss, increased sweating and drowsiness may develop, and there may be dulling of the intellect or dementia. Progression is slow, severe weakness occurring only at a late stage. Few people are confined to a wheelchair before their fifties, but the presence of cardiac and respiratory symptoms with a slow deterioration in mental and physical energy may add to the level of disability. For most people this is severe within fifteen to twenty years of onset, and death from respiratory or cardiac failure may occur early.

46.7.7 Spinal Muscular Atrophy

(i) Although not a dystrophy, this condition may at first resemble one, and it causes similar problems. It is the childhood version of Motor Neurone Disease [See Chapter 15], and has three forms, the infantile, the intermediate and the juvenile, affecting both sexes.

(ii) The infantile form (Werdnig-Hoffman disease) is usually apparent soon after birth. There is severe weakness of all muscles, except those of the face. Most of these babies die in infancy, but for the few who survive longer, complete helplessness persists.

(iii) "Intermediate" spinal muscular atrophy is a severe, chronic, generalised form of the disease which normally presents in the first year of life with severe muscle weakness and skeletal deformities. Despite the fact that they have severe weakness and physical disability, these children are usually intellectually normal.

(iv) The juvenile form (Kugelberg-Welander Syndrome) is much milder, and occurs between early childhood and adolescence. It usually begins with difficulty in walking, climbing stairs and rising after a fall. Progress is spasmodic, periods of deterioration being interspersed with periods when it seems to be arrested, and the ability to walk is frequently retained into adult life. Gradually increasing disability is, however, inevitable and survival limited to some thirty years or so from onset.

46.7.8 Care Needs and Mobility Considerations

(i) Because of the range of disabilities caused by these conditions it is impossible to generalise. Needs arise as muscle groups degenerate, and the type and level of need in any individual will depend on which muscles are involved and what stage has been reached in the disease process. Either care or mobility needs may be the first to arise and, in the more severe forms of these conditions, both may be extensive.

(ii) It is important that these people are kept under regular review by medical, orthopaedic and physiotherapy agencies. It is essential to maintain good

posture, mobility either independently or with aids, and as good a quality of life as possible.

46.7.9 Duration of Needs

All these conditions are progressive, and cause gradually increasing disability. Needs, once established, do not abate. The level of need will increase as the disease progresses.

46.7.10 Further Evidence

In the case of a child, the most valuable source is likely to be a professional involved in community care, either at a Child Development Centre or in school; for adults, it may be a social worker or GP.

46.8 Osteogenesis Imperfecta

46.8.1 Introduction

The term osteogenesis imperfecta (brittle bone disease) refers to a group of rare inherited disorders with the common feature that bones are excessively fragile. The overall incidence of osteogenesis imperfecta is between 1 per 20,000 and 1 per 50,000 of the population. It takes several different forms and varies considerably in its severity, although the commonest form is usually relatively mild.

46.8.2 General

(i) In the mild forms the tendency of bones to fracture is not great and any fractures that do occur heal well leaving little or no disability. This group may have little problem in childhood, fractures occurring later in life. This form of the condition is often associated with deafness and with damage to the enamel of teeth.

(ii) The more severe cases suffer repeated fractures from minor injuries. They may develop severe deformities because the fractures do not heal properly. This often leads to the need for repeated operations to correct the deformities. It may even be necessary to support the skeleton externally with inflatable "space suits". An alternative approach is to accept that a severely affected child will never walk and that the provision of a suitable electric wheelchair is the best means of increasing independence and mobility.

(iii) The most severely affected children are born with multiple fractures and gross deformity and shortening of limbs due to these. Most die at or shortly after birth but a few survive infancy grossly disabled and unable to do anything without the risk of further fractures occurring.

46.8.3 Care Needs

These will depend on the severity of the condition. In most instances all that is needed is some extra supervision in situations when the possibility of falls is greater than usual. This extra supervision varies with individual circumstances and depends to some extent on the age of the child. In the more severely affected child, in particular those with a history of repeated fractures, there is likely to be a need for considerable additional supervision for most of childhood. If there is evidence of deformity and shortening of bones there may also be a need for help in connection with bodily functions. Those with the most severe form of the disease that survive infancy will be in need of a great deal of attention both by day and by night.

46.8.4 Mobility Considerations

These again will depend on the severity of the condition. For those with the mildest form of the disease there may be some need for supervision when walking, but in most instances this is unlikely to be significantly greater than that needed by a healthy child of the same age. For those who do need supervision to avoid the danger of falls, there may be a need for supervision when walking. There may also be a danger to health caused by the effort of walking as the "stresses" of walking may alone be sufficient to cause fractures. Those affected to this degree may well be using a wheelchair already since the severity of their disability results in their being unable to walk.

46.8.5 Duration of Need

In less severe cases where it is established that a young child needs a significant degree of supervision, this may be required to about the age of 8. By this age the child may be aware of the dangers and may be able to take appropriate action to avoid them. Each case, however, must be considered individually. In the more severe cases, particularly those with considerable care needs or those unable to walk, the disability will be permanent.

46.8.6 Further Evidence

The needs of those affected severely should be clear. In less severe cases a report from the GP or hospital attended may well provide details of the frequency and severity of previous fractures and their consequences. This information should give an indication of the likely risks in future.

47. DISORDERS OF BLOOD CLOTTING IN CHILDREN

47.1 Contents

47.2 Introduction

47.2.1 **Haemophilia A** is the most common disorder of blood clotting for which DLA may be sought. Others are **Haemophilia B (Christmas disease)** and **von Willebrand's disease**. Their effects are similar. Due to deficiencies of certain blood factors which are important for the normal clotting of blood, there may be a requirement for these to be replaced by injection

47.3 Care Needs

47.3.1 The presence of a bleeding disorder does not of itself mean that a child has care or mobility needs. At least half of those affected by haemophilia are able to live a normal life; they require special attention only at particular times as, for example, when they require tooth extraction or surgical operation. However, more severely affected children often require a great deal of attention and supervision.

47.3.2 In cases in which the factor deficiency has been assessed as severe (ie. less than 5% Factor VIII) and there is a history of repeated spontaneous or accidental bleeds, there is need for continual supervision to avoid situations likely to provoke further bleeds and to take action when bleeding does occur; the need is likely to continue to about the age of 12 years. By this age the child should be sufficiently aware of the limitations imposed by his condition to be relied upon to avoid dangerous situations and to summon help if required. In cases in which the factor deficiency has been assessed as moderate or mild and bleeding has been occasional, for example once or twice a year following injury, it is unlikely that the child will have care or mobility needs substantially greater than those of a healthy child.

47.3.3 Exposure to injury is greatly reduced at night. In the event of a spontaneous bleed starting at night, the child can call for assistance.

47.3.4 Modern treatment is usually successful in avoiding permanent damage to joints. However, where this has occurred, there may well be a significant need for attention and problems with mobility.

47.4 Mobility Considerations

47.4.1 For children with severe haemophilia (less than 5% Factor VIII) there is a significant danger of spontaneous and serious bleeding into joints when they walk.

47.5 Children Who Are HIV Positive

47.5.1 Some children with severe haemophilia have become Human Immunodeficiency Virus positive (HIV+) as a result of being given contaminated blood products. As they grow up and become aware of their condition, resentment builds up to the extent that they may refuse to give their own injections for a period or to take necessary care to avoid injury. In these circumstances they may require supervision to a later age. Some have now developed symptomatic HIV Infection or AIDS and may have care and mobility needs because of this. [See Chapter 32].

47.6 Further Evidence

47.6.1 Affected children are under the care of a special centre. A diagnosis specific factual report from such a centre may well help to establish the level of need.

48. THALASSAEMIA AND SICKLE CELL ANAEMIA

48.1 Contents **Paragraph**

48.2 Thalassaemia

48.2.1 Clinical Description

The thalassaemias are hereditary anaemias due to abnormalities in the synthesis of haemoglobin (the oxygen-carrying protein in red blood cells). The severe effects of thalassaemia, which because of treatment are rare in the UK, are the result of severe anaemia which stimulates the production of red blood cells; this expands the bone marrow mass resulting in osteoporosis (thinning of the bone) with the potential for spontaneous fractures. Retardation of bone growth, marked enlargement of the liver and spleen and a tendency to acute crises occur. For example infection can cause a catastrophic fall in the number of red blood cells. Modern treatment makes these features unusual.

48.2.2 Care Needs

(i) Correction of the anaemia by regular blood transfusion, usually every 6 to 8 weeks, avoids the complications and allows the child to develop normally. As a result of regular blood transfusions iron overload becomes a problem because humans have a limited ability to excrete iron. This can be overcome by use of the iron chelating drug, desferrioxamine, which is administered under the skin by an infusion pump. The infusion is given over a period of several hours during the night. The pump is set up before the child goes to bed and the needle removed first thing in the morning. Each of these actions normally takes no more than 15 minutes.

(ii) Although the pumps are reliable and the occasional failure would not have a significant effect on the course of the disease, it would not be unreasonable for a parent to look in on the child several times through the night whilst this therapy is in progress. Consequently, unless it is evident that the child has completely adapted to the presence of the pump, watching over by night may be considered appropriate. Children have usually adapted to the presence of the pump by the age of 12. Beyond this age, they would normally not be expected to have care or mobility needs in excess of those of a healthy child unless they had developed any of the complications of the disease. The care needs would then depend on the nature of the complications and the severity

of the symptoms produced.

48.2.3 Mobility Considerations

Thalassaemia does not in itself cause any problems with walking.

48.3 Sickle Cell Anaemia

48.3.1 Clinical Description

(i) Sickle cell anaemia is an inherited disorder of haemoglobin (the oxygen-carrying protein in red blood cells). To develop sickle cell anaemia, a person must inherit a gene for the abnormal protein from each parent. People with only one such gene are said to have sickle cell trait. Only in exceptional circumstances would a person with sickle cell trait develop problems.

(ii) In sickle cell anaemia, the abnormal haemoglobin is less soluble than the normal form and this causes deformity (sickling) of the red blood cells in certain circumstances. The effect is to plug the arterioles and capillaries, depriving tissues of their vital oxygen supply. As a result tissue damage occurs.

(iii) These episodes are called "crises". During a crisis, a person with sickle cell anaemia may experience fever, abdominal pain, vomiting and severe pain in the long bones, back and joints. The person often becomes suddenly and severely anaemic. Other features may include stroke, paralysis of the cranial nerves (nerves controlling the head muscles), chronic ankle ulcers and avascular necrosis (death of bone) at the top of the thigh. Repeated crises lead to a chronic deterioration in general health. In adults there is a severe (though variable) anaemia, and progressive lung and kidney failure. As a result, life expectancy may be reduced.

48.3.2 Care Needs and Mobility Considerations

(i) In the early years of the disease, during and immediately after an acute sickle cell crisis, the person is very ill, unable to walk and requires high levels of care. However, the individual crisis is self-limiting, and will remit within a week or so. Between crises the person will be expected to function normally, so it is important to gauge the severity, frequency and duration of crises.

(ii) As the disease progresses, while the acute crises may continue on a regular basis, the toll on general health becomes evident. This affects both mobility and care needs. For example, avascular necrosis at the top of both thighs may seriously impede the ability to walk, whilst chronic pain, fever and general debility will generate increased care needs.

48.3.3 Duration of Needs

Whilst it is true to say that sickle cell disease is generally progressive, the condition may remain static over several years.

48.3.4 Further Evidence

In determining the severity, frequency and duration of sickle crises, a factual report from a GP or hospital medical or nursing specialist attendant may be helpful. In chronic disease where general health has become impaired, a visit from an examining medical practitioner may be required in order to assess fully the needs of the person with the disease.

49. SKIN DISEASE IN CHILDREN

49.1 Contents

49.2 Introduction

49.2.1 Essentially, the same principles apply as for adults with the proviso that young children cannot be expected to deal with their own treatment in the same way as adults. [Chapter 30]. As with adults, the severity of skin diseases can vary enormously. At one extreme, small patches of reddened or dry skin on the scalp and nappy areas are very common, particularly in babies, and do not produce any significant problems. At the other extreme, the skin condition can be severe and widespread leading to a need for frequent treatment and causing considerable upset both for the child and the parents.

49.2.2 Itching is a particular problem for children who find it very difficult not to scratch, if indeed they are old enough to understand that they should not. Because of this, a child's hands may have to be bandaged to prevent scratching or pulling off dressings. Obviously this will add significantly to the care needs.

49.3 Care Needs

49.3.1 When the skin condition is severe and widespread, there is likely to be a need for more frequent bathing and nappy changing than would normally be the case. In addition preparations and dressings may have to be applied to the skin and the hands may have to be bandaged to prevent the child scratching or pulling off the dressings. This may well add up to a substantial amount of help, in some cases confined to morning and evening but in others spread through the day. Skin diseases do not give rise to any serious danger so there should be no need for additional supervision.

49.3.2 Although actual treatment of the skin condition during the night hours may not be necessary, itching may disturb sleep and lead to a need for comforting. Nappies may also need to be changed more frequently in order to protect the damaged skin.

49.4 Mobility Considerations

49.4.1 In a few cases there may be mobility needs when for instance the skin disease affects the soles of the feet or when bandaging of the lower limbs is extensive.

Rarely is this likely to last for more than 3 months at a time.

49.5 Duration of Need

49.5.1 Skin conditions in children often respond to treatment, or improve as they get older. The likely duration of need will depend on the circumstances of a particular case. By the age of about 12 years a child may well have learned to treat his own skin and there is unlikely to be a need for comforting at night.

49.6 Further Evidence

49.6.1 Understandably, where young children are concerned, parents may be overprotective and apply preparations to the skin more frequently than is required or wise. A report from the GP may establish whether this is the case and may also help to determine the likely duration of need.

50. MALIGNANT DISEASE (CANCER)

50.1 Contents **Paragraph**

50.2 Introduction

50.2.1 Malignant disease, cancer and neoplasia are all general terms used to describe the uncontrolled multiplication of cells that have become insensitive to the normal growth control mechanisms. This growth (tumour) expands and invades and destroys adjacent tissues causing local effects that vary according to the site of the tumour. Cancer can also spread to distant areas of the body where further tumours (metastases) develop. These will produce additional effects depending on their site.

50.2.2 Malignant disease can develop in any organ of the body including the blood cells and the skin. Metastases (secondary deposits) can occur anywhere although some organs, notably the liver, lungs, brain and bones are particularly affected.

50.2.3 For most cancers the diagnostic label given describes the type of cancer and where it has come from. In clinical medicine this is obviously important. Here, the significance of the diagnosis is to indicate that a person is suffering from a form of cancer. Specifying the type of cancer is not so important, although it can be useful in pointing out what local symptoms can be expected.

50.2.4 Tumour forming cancers usually have a name ending in -OMA. Some of these indicate the general type of tissue giving rise to the tumour. They are usually qualified in some way to indicate the specific site of origin. **Carcinoma** arises from skin or membranes such as those lining the gut or lungs. Hence bronchial carcinoma is a tumour arising in the large air passages of the lungs and gastric carcinoma is a tumour arising from the lining of the stomach. **Sarcoma** arises from connective tissue, bone and cartilage, **osteo-sarcoma** from bone and **chondro-sarcoma** from cartilage. Lymphoma develops in the lymphatic system. Other names ending in -OMA indicate the specific type of tumour. **Melanoma** is a tumour of the cells that produce skin colour, **mesothelioma** develops in the membrane covering the lung.

50.2.5 Cancers of blood cells usually affect the white blood cells and are called **leukaemias**. They are usually qualified by the type of cell affected and their

speed of onset. Thus acute myeloid leukaemia is of sudden onset and affects myeloid cells and chronic lymphatic leukaemia is of much slower onset and affects lymphocytes.

50.2.6 Cancer can occur at any age but, in general, its frequency increases with age. Nevertheless, it is still the second most common cause of death amongst children. Accidents are the commonest cause.

50.3 General

50.3.1 Malignant disease is progressive and, untreated, results in death in most cases. Even with treatment many people still die from the effects of their cancer although certain tumours are now very amenable to treatment. Treatment of leukaemia and lymphoma in particular is now so successful that many people can be considered to be cured. For large numbers, however, there is a relentless deterioration in health leading to severe disability and death. For some this may take many months or years but for others death occurs within weeks of the first symptoms being reported.

50.3.2 Most of the harmful effects of a malignant tumour are caused by its local effects on surrounding structures. The consequences of these local effects are entirely dependant on where the tumour is situated in the body. In some instances, because of the reserve capacity of many organs, the presence of a tumour is quite compatible with apparent good health until the cancer is so advanced that it is untreatable. In others, a tumour can cause symptoms very early in its development because of damage to vital structures adjacent to it.

50.3.3 Tumours may also give rise to profound generalised disturbances either directly by producing large quantities of biologically active substances such as hormones or indirectly by damaging or infiltrating other organs, causing for example liver failure or profound anaemia. Advanced cancer is also associated with a generalised state of ill-health called cachexia. This is usually associated with advanced disease and is characterised by loss of appetite, loss of weight, anaemia and a general feeling of ill-health. This state is extremely debilitating but can go on for many months.

50.3.4 Cancer can spread to other parts of the body, the effects depending on the particular part of the body involved. The most common sites are:-

(i) **Brain**: the needs for help may be similar to a person who has had a stroke or suffers from epilepsy or dementia - indeed, all three of these may occur.

(ii) **Lung**: causing extreme breathlessness.

(iii) **Bones**: this causes severe pain (requiring very potent pain killers) and spontaneous fractures.

(iv) **Liver**: leading to jaundice and extreme weakness.

50.4 Treatment of Cancer and Its Effects

50.4.1 The treatment of cancer includes surgery, radiotherapy (X-ray treatment) and chemotherapy (drug treatment). Treatment may be directed towards a cure or to control symptoms and relieve distress (palliative treatment). This will depend much on the type of cancer, its site in the body and how far it may have spread.

50.4.2 Curative surgery involves removal of the cancer and repairing damage to adjacent structures. It may be prolonged and involve complex reconstructive surgery. Although debilitating in the immediate post-operative period it can, if successful, lead to a cure or a long period of remission from the disease. Other treatments (see below) may be used in conjunction.

50.4.3 Radiotherapy involves the use of X-rays to destroy a tumour. Modern treatment is designed to do this with the smallest possible dose of radiation but people still suffer side effects, notably burning of the skin, nausea and vomiting. However, these should soon settle when a course of treatment is finished. It may be used alone or in conjunction with surgery or chemotherapy.

50.4.4 Chemotherapy involves the use of potent cytotoxic (cyto= cell) drugs to kill the cells of a cancer. It is particularly used in the treatment of leukaemia and lymphoma or when a cancer is widespread. These drugs attack normal cells as well as cancer cells although to a lesser extent. Side effects are common and include nausea and vomiting, anaemia and loss of hair. The drugs are usually given as a course over a few days with two or three weeks rest in between. Side effects are often severe when the treatment is being given but usually subside between courses.

50.4.5 Palliative treatment is designed to alleviate the symptoms resulting from a cancer when it is clear that curative treatment is not possible because of the advanced stage of the disease. Sometimes surgery may be needed to relieve obstruction or to set a fracture caused by a deposit of cancer in a bone. More often the problem that needs to be dealt with is severe pain caused by the pressure of a large tumour or by infiltration of structures by the tumour. This treatment may involve the use of radiotherapy to shrink a large tumour but more often it involves the use of strong pain-killing drugs derived from morphine. These may be given as tablets, as intermittent injections or by pumps that inject a continuous small dose of the drug.

50.5 Care Needs

50.5.1 The needs of people suffering from cancer vary enormously. They depend on the site and size of the primary tumour, on the site, size and number of metastases (secondary tumours) and on the generalised effects of the cancer. The effects of treatment also influence care needs even though this may be intermittent or of short duration. Depending on the particular combination of

these factors in an individual case, disability can vary from none to total disablement.

50.5.2 Although attention needs are usually predominant, involvement of the brain, either by the primary cancer or its secondary spread, may result in the development of epilepsy, behavioural change or a tendency to fall. These problems may well give rise to a need for supervision.

50.6 Mobility Considerations

50.6.1 Generalised weakness or severe pain will make walking extremely difficult for many people. Secondary deposits in the spine, causing damage to the spinal cord, may lead to total paralysis of the legs.

50.7 Care and Mobility Needs Arising as a Result of Treatment

50.7.1 As stated above treatment of cancer is by chemotherapy, radiotherapy and surgery. A person may be getting one of these treatments or a combination of them. The drugs and radiotherapy used in the treatment of cancer often produce side effects of severe nausea, vomiting, loose bowels and a feeling of extreme tiredness, leaving the patient feeling generally very ill. These symptoms come on shortly after treatment and can last from a few days to a few weeks. It may be helpful to find out how often the person is having treatment. Initially it may be a couple of times a week and then gradually there are longer periods between treatments. A person will be severely incapacitated during the treatments and may need help with bodily functions day and night and the mobility will also be severely impaired.

50.7.2 If the person's general condition is already poor, due to the underlying cancer, recovery from surgery is much longer than usual, and the need for help with care and mobility is then likely to be present.

50.7.3 Extremely potent pain relieving drugs (morphine or its substitutes) are given and these often cause a degree of drowsiness and confusion. This can lead to dangers as the person may be prone to falls and in these cases supervision is appropriate.

50.7.4 In children there is the added component of emotional needs ie being separated from other siblings and their friends. The carer also has to be meticulous with procedures that involve giving medication other than by mouth, to prevent any infections.

50.8 Duration of Need

50.8.1 Treatment of leukaemias and lymphomas is very intensive and adds considerably to the disability caused by the disease itself. However, for many the treatment is successful, sometimes in a matter of months, and long periods of remission from the disease can be expected. In these cases it can be difficult to judge how long help will be needed in an individual case.

50.8.2 For most other forms of cancer a similar situation arises after curative surgery. There may be considerable disability immediately after the operation but if the cancer does not recur recovery can be expected to be fairly rapid. For some people, particularly those with other disabilities, there may be a continuing need for help. For example, help may be needed with a colostomy following bowel surgery. Surgery for breast cancer can lead to loss of effective use of the arm.

50.8.3 In other cases a need for a significant amount of help indicates advanced disease whose progress is unlikely to be halted by any form of treatment. In this situation, which may develop rapidly, once the need for help has been established it will be continued.

51. FURTHER EVIDENCE AND ADVICE

51.1 Contents

51.2 Introduction

51.2.1 At various points in this book suggestions are made concerning the sources of further evidence which are most likely to be of assistance in particular types of case. The purpose of this chapter is to describe the various sources of further evidence and to indicate the sorts of information which can be obtained from each one. Providers of further evidence should not be asked to answer direct questions on whether the qualifying conditions for the benefit are satisfied. In general terms they can be asked for information which will fill gaps in the evidence which would otherwise be incomplete. They can also provide evidence which will help the adjudication officer deal with inconsistencies or contradictions in the information already held.

51.3 Sources of Further Evidence

51.3.1 General Practitioner Factual Reports (GPFRs)

(i) A special fee payable to individual GPs has been agreed whereby factual information based on a patient's clinical records will be provided. The fee does not extend to the provision of an opinion and so, unless the information is already contained within the clinical records, the GP will not be in a position to provide it. It has to be understood that individual entries in a patient's clinical record are relatively brief and will usually concentrate on diagnosis, clinical findings and treatment plan. The records will not really contain any meaningful information relating to care and mobility needs. In general therefore GPFRs can provide useful information on the diagnosis and overall severity of a person's disabling conditions. It will not usually be appropriate to ask specific questions about the help a person requires unless there appears to be gross under-or over-representation of those in the claim pack.

(ii) Where a person has a number of different conditions which are being investigated and treated by a variety of hospital departments, the GP's records will be the place where all this information is co-ordinated. In these circumstances the GP may well be able to indicate the relative importance of the various conditions in terms of their effect on the patient's day to day life.

51.3.2 Hospital Factual Reports (HFRs)

The Benefits Agency does not have to pay for individual HFRs. Hospitals are funded separately to provide this service but again this extends only to the

provision of factual information. Although usually more detailed than GP records, hospital notes still concentrate on recording information on diagnosis, clinical findings and treatment. They may contain a great deal of detailed information about the various types of investigation which have been undertaken and which are usually of no relevance to the issues the adjudication officer has to decide. In general therefore HFRs can provide similar information to GPFRs. The hospital rather than the GP is likely to be the most appropriate source of information where the person suffers from an uncommon condition, where the diagnosis is complicated or where specialised forms of treatment are involved.

51.3.3 Consultants Reports

It is possible to ask a consultant to examine a person and to answer specific questions relating to the care and mobility needs. However, it has to be appreciated that such reports are expensive and take a long time to complete. More importantly though, it has to be recognised that a consultant's expertise will be concentrated in the areas of diagnosis, investigation and treatment. Whilst consultants usually provide excellent information in these areas, they often do not appreciate the full significance of questions relating to care and mobility needs. Experience has shown that such questions are not answered as fully as adjudication officers would want. Consequently, the situations where a consultant's report is the most appropriate source of further evidence are likely to be few and will usually be confined to cases where the diagnosis is particularly uncommon.

51.3.4 Examining Medical Practitioner (EMP) Reports

EMPs have been given training in the discipline of disability medical analysis. Within this discipline, the diagnosis, whilst being an essential starting point, is only of secondary importance. EMPs will be able to assess what effects a person's condition is likely to have on day to day living. They will be able to provide a critical appraisal of whether a person's claimed care and mobility needs are reasonable in the light of the diagnosis and clinical severity of the particular disabling conditions. Consequently if the evidence relating to the level of needs is incomplete, inconsistent or contradictory, an EMP report is likely to be most appropriate source of further evidence to deal with these issues.

51.3.5 Reports From Other Professionals

Whilst for most people, professional advice is likely to come from the GP, there will be a significant number where other professionals are involved. These may include nurses, physiotherapists, occupational therapists, psychologists and specialist teachers. In some cases these will be in a much

better position to provide meaningful information than the GP. In each case, a critical assessment is needed on how useful a report from such a professional is likely to be. This will include an assessment of how closely they are involved in day to day care and whether they have been instrumental in deciding how a person's condition is managed, rather than simply carrying out a plan which has been devised by others. There are two situations where such a report is likely to be particularly helpful. First, community psychiatric nurses may be heavily involved in the community care of people with severe mental illnesses and may have a detailed knowledge of the daily needs. Secondly, specialist teachers in children with learning disabilities are extremely well placed to report on the educational and behaviour problems of such children.

51.4 Advice from Medical Services Doctors

Although Departmental Medical Services doctors do not have the opportunity to examine claimants, adjudication officers should be aware that they are particularly skilled and knowledgeable in the field of disability medical analysis. Consulting a Medical Services doctor at an early stage in a difficult case, either formally or informally, can often prevent a time consuming and potentially fruitless search for inappropriate further evidence. Medical Services doctors will be able to advise in a number of areas. They can interpret and explain medical terminology within the evidence, describe the range and extent of care and mobility needs which are likely to arise from a particular diagnosis, analyse the claimed needs for any inconsistencies or contradictions, identify the most appropriate sources of further evidence along with the specific questions to be asked, and finally can explain and interpret the further evidence once it has been received.

52. BRAIN INJURY

52.1 Contents **Paragraph**

Related conditions considered in other chapters

52.2 Introduction

52.2.1 Brain injury can lead to a variety of physical, cognitive and psychological impairments with significant resultant disabilities. The most common cause of brain injury is trauma to the head occurring as a result of falls, assaults, road traffic accidents etc. In order to aid clarity this section will concentrate on the effects of head injury. It is important however to remember that acquired brain injury can result from a number of other causes including non accidental injury, infections such as meningitis, inflammation of the brain (encephalitis), cerebral anoxia/ischaemia (when the brain is starved of oxygen - due to haemorrhage, circulatory collapse or stroke). A wide spectrum of disabilities may result and the reader may find it helpful to refer to some of the other chapters listed above for more detail on specific disabilities.

52.2.2 The adverse effects of head injury can be due to the primary trauma e.g. skull fracture, or to secondary damage arising from complications such as cranial haemorrhage, bruising or swelling of the brain. There is considerable variation in the severity of head injuries and the effect on function. The severity of the head injury can be classified in a number of ways depending on the length of time for which the person is unconscious and the duration of post-traumatic amnesia (memory loss) caused by the injury. Post-traumatic amnesia is the period of time after the injury before continuous day to day memory returns.

52.3 Mild head injury

52.3.1 A mild head injury can be defined as an injury causing unconsciousness of fifteen minutes or less, or post traumatic amnesia for less than six hours. Most head injuries seen in primary care or accident and emergency departments are minor/mild, and require no treatment apart from an assessment and advice. Recovery usually occurs within days or weeks. Even amongst those admitted to hospital with a head injury (a quarter of the total) eighty-percent will still be classified as minor.

52.3.2 Following minor head injuries some people may suffer from various symptoms. These may include headache, decreased concentration, disturbed sleep, memory impairment and dizziness. Symptoms of anxiety and depression may also develop. These effects of the injury are often short lived, lasting a few weeks or months, and tend to improve spontaneously. Treatment with antidepressant medication and/or counselling can also be very effective in aiding recovery.

52.4 Care Needs and Mobility Considerations

There are unlikely to be any requirements for attention or supervision following a mild head injury. Ability to walk is not affected and the person would not be expected to have any difficulty in finding their way around out of doors.

52.5 Serious head injury

52.5.1 People with more serious head injuries, (unconsciousness lasting for many hours or days and post traumatic amnesia lasting for up to a week or more) are admitted to hospital. A small number of cases may require surgical treatment to alleviate the adverse effects of skull fracture or haemorrhage affecting the brain.

52.5.2 Any part of the brain can be affected following a more severe head injury, and the pattern of damage may vary considerably from person to person. Serious neurological impairments that may result include deafness, visual loss, quadriplegia, hemiplegia, sensory loss in the limbs, difficulty in swallowing, epilepsy, hydrocephalus, defective balance and language disorders. Prolonged periods of unconsciousness, memory loss and confusion are more likely to be associated with severe and persistent disabilities. Whatever the extent of physical impairments some degree of cognitive impairment (see below) is common after moderate/severe head injuries.

52.5.3 Treatment often includes courses of intensive physiotherapy and rehabilitation lasting over weeks or months. Serious head injuries are

a leading cause of disablement amongst young adult males. Rehabilitation aims to enable people to recover previous skills and to learn new skills or new ways of managing.

52.5.4 Serious head injury usually causes cognitive impairment with substantial disabling effects. In its broadest sense **cognitive impairment** means that the affected individual has difficulty in thinking, in understanding, in reasoning, in carrying through logical thought processes and in the perception of self and others. The difficulties include memory loss (in particular remembering new information), poor attention, diminished concentration, language problems (recognising and using appropriate words) and perceptual skills. Affected individuals may be unable to solve problems, find their way around and organise the usual tasks of day to day life. The ability to learn may be slow and ineffective. Substantial cognitive impairment can exist in the absence of any obvious physical disability, and affected individuals may have little or no insight into the extent of their disabilities.

52.5.5 Personality changes may also occur leading to irritability, impulsive actions, socially disinhibited or aggressive behaviour, loss of initiative, lethargy and poor motivation. Those with brain injury may show inappropriate emotions e.g. laughing when learning bad news, and exhibit rapid changes of mood for no apparent reason. Loss of initiative and poor motivation in combination with problems such as memory loss further hinder the person's ability to carry out activities of daily living. Functional limitations may also be exacerbated by the subsequent development of anxiety and depression.

52.5.6 It is apparent that the more serious head injury can lead to and be associated with a wide variety of disabilities. Each person will require to be assessed individually on the basis of the medical evidence to determine the extent of the cognitive problems, and the additive effects of any physical and mental impairments that may lead to greater functional restriction.

52.6 Care needs

52.6.1 After more severe injuries some individuals may function well in a structured environment and manage their own bodily functions. Others may need much attention from their carers to wash, dress and prepare food. Planning a meal and cooking it safely may be a problem. Often there is a need to prompt people to initiate and complete such tasks; they may be easily distracted from the task in hand. Coexisting physical disabilities such as a hemiparesis (loss of power on one side of the body) or visual loss will increase care needs. Supervision may be necessary to avoid common dangers within the home.

52.6.2 Epilepsy developing after a head injury is described as post-traumatic epilepsy. It may occur soon after the trauma, within the first week, or at a later stage, (50 - 60 percent) within the first year after injury. Late epilepsy is more common where there has been bleeding into the brain or surgical intervention has been required. Those with epilepsy may need to be reminded of the importance of taking medication regularly.

52.6.3 Individuals with language problems (recognising and using appropriate words), unclear speech due to difficulties in articulation and slowness in processing information, whether verbal or written, may need help with communication. Deafness may also result in a requirement for help in this area.

52.7 Mobility

52.7.1 Head injury itself may not be associated with any particular difficulty in walking. Restricted mobility is likely to be due to coexisting neurological damage causing weakness or paralysis of the lower limbs. Sometimes a disturbance of balance may make walking more difficult.

52.7.2 Cognitive impairment may lead to a requirement for guidance and supervision out of doors. An individual might be able to manage a short trip to a local shop alone, but would not be able to go elsewhere because of memory loss and spatial problems. Disruptive or uninhibited behaviour may mean that it is inadvisable for a person to be out of doors without supervision. Visual loss secondary to brain injury may exacerbate the inability to get around out of doors.

52.8 Duration

Rehabilitation programmes for serious head injury can last from several months up to a year. The greatest amount of recovery occurs in the first six months after the injury. Improvement does however continue to a lesser extent over the next six to twelve months. After that the disabilities, whether physical, cognitive or behavioural, tend to be permanent.

52.9 Further evidence

52.9.1 If a person is under hospital care, factual reports can be obtained from neurologists, neurosurgeons, specialists in rehabilitation medicine and nurse specialists attached to these clinics. Occupational therapists, physiotherapists and speech therapists, often working in association with social workers, can also be a useful source of evidence. These health care professionals may be based in specialist units that deal with head injuries. These reports are often most useful in the first one or two years after a serious head injury. A (neuro) psychologist may

undertake specialised testing of a person's cognitive function in the recovery/rehabilitation phase. This type of report, if available, can be especially useful.

52.9.2 If the person whose condition is stable is no longer under hospital care other sources of evidence need to be sought. General practitioner factual reports may be the main source of information for those who no longer attend specialist services. Community paediatricians or schools may be able to provide factual reports for children.

52.9.3 Social workers may be involved with those who live in sheltered accommodation, or who need extra support to live in the community in their own homes. An assessment by an Examining Medical Practitioner is appropriate when disabilities are stable and/or long standing, and when other factual reports give insufficient detail to ascertain the overall level of disability.

52.9.4 Factual reports about the effects of minor head injuries are most likely to be obtained from general practitioners.

GLOSSARY OF TERMS

Abscess	A localised collection of pus and necrotic (dead) tissue, usually due to an infection, which can occur in any part of the body. Its effects will depend on its location. Treatment will often involve incision of the abscess to drain away the pus.
Achondroplasia	A form of arrested development of the long bones leading to short stature.
Acidosis	A condition in which the blood is more acidic than normal, due to a build up of carbon dioxide as a result of respiratory failure, or of acid substances, for example in kidney failure or as a complication of diabetes mellitus (diabetic ketoacidosis). The chemical imbalance caused by acidosis has wide ranging effects on organ function and, if untreated, eventually results in coma.
Acoustic	Relating to sound or the sense of hearing.
Acuity	Clearness or sharpness; usually of vision.
Acute	Having rapid onset, severe symptoms, and a short course; not chronic.
Addisons disease	A disorder caused by deficient secretion of hormones by the adrenal gland, resulting in weight loss, weakness, and low blood pressure. It is treated by replacement steroid therapy.
Adrenal glands	Two glands located above each kidney which secrete hormones, including cortisone (cortico steroids) and adrenalin.
Agoraphobia	Fear of open spaces.
Albinism (Albino)	Abnormal partial or complete absence of pigment in skin, hair and eyes.
Albumin	One of the body's proteins. The most abundant of the proteins in the blood plasma.
Albuminuria	Presence of albumin in the urine usually indicating disease of the kidneys.

Allergen	A substance which, when introduced into the body, causes the production of antibodies and provokes an allergic state in sensitive individuals. Some of these substances are derived from pollens, from animal hair or fur, or are found in the diet.
Allergy (Allergic State)	Sensitivity to a particular foreign substance [Allergen] which acts as a poison producing abnormal reactions. Asthma and hay fever are often allergic conditions.
Ambulatory	Capable of walking.
Amenorrhoea	Absence of menstruation.
Amnesia	Loss of memory.
Anaesthesia	A partial or total loss of feeling or sensation.
Analgesia	Pain relief.
Analgesic	A drug that relieves pain [such as aspirin, paracetamol, morphine].
Anastomosis	An end-to-end union or joining up of blood vessels or nerves.
Aneurysm	A localised ballooning of the walls of an artery, most commonly affecting the aorta. Effects range from no symptoms, to pain due to pressure on nearby nerves, to sudden death if the aneurysm ruptures.
Angina Pectoris	A pain in the chest on exercise related to reduced circulation of blood in the coronary arteries to the heart.
Angiography	X-ray examination of blood vessels after injection of a substance which shows up on the x-rays.
Ankylosis	Severe or complete loss of movement at a joint due to the abnormal joining of bones to each other.
Anomaly	An abnormality.
Anoxia	Deficiency of oxygen.
Anterior	Nearer to, or at the front of the body.
Antibiotic	A drug that inhibits the growth of, or kills micro organisms such as bacteria (germs).
Antibody	A protein produced by the body in response to a foreign substance (antigen). The antibody combines with the antigen to destroy or neutralize it.

Anticoagulant A substance that is able to delay, suppress or prevent the clotting of blood.

Anti-convulsant drugs Drugs used to treat epilepsy.

Antigen A substance that when introduced into the body causes the formation of antibodies.

Anuria An abnormally low, or absence of urine output.

Anus The outlet of the rectum.

Aorta The main trunk of the arterial system of the body which carries away blood from the heart.

Aperture An opening or orifice.

Apex The pointed end of a structure.

Aphasia Loss of ability to express oneself properly through speech.

Appendicitis Inflammation of the appendix which is a small blind tube in the gut.

Apnoea A temporary suspension of breathing, for several seconds. It occurs in pre-term (premature) infants in whom the automatic breathing control mechanism is immature; it may require use of an apnoea alarm to alert the carer. **Sleep apnoea**, which is seen in adults, is seldom of serious significance.

Arachnoiditis A condition in which there is progressive fibrosis (thickening) of the arachnoid membrane surrounding the spinal cord, causing pain and muscle weakness through involvement of nerve roots. Many cases are thought to be a result of use, until recently, of irritant dyes during myelography [q.v.].

Areflexia The absence of reflexes.

Arm The portion of the upper limb from the shoulder to the elbow.

Arrhythmia Irregular heart rhythm (also called dysrhythmia).

Artery A blood vessel that carries blood away from the heart.

Arthralgia Pain in one or more joints.

Arthritis Inflammation of a joint.

Arthroscopy A procedure for examining the interior of a joint.

Articulate	To join together.
Articulation	A joint.
Artificial pacemaker	A device that produces and delivers electrical signals to the heart to maintain a regular heart beat.
Ascites	Abnormal accumulation of fluid in the abdomen.
Aseptic	Free from any infectious material.
Asphyxia	Unconsciousness due to interference with the oxygen supply to the body.
Asthenia	Lack or loss of strength; debility.
Astigmatism	An irregularity of the lens or cornea of the eye producing faulty vision.
Ataxia	Unsteadiness; lack of muscular coordination; lack of precision.
Atelectasis	A collapsed or airless state of all or part of a lung.
Atherosclerosis	A disease process in which fatty substances are deposited in the walls of arteries which can lead to obstruction of blood flow.
Atrophy	Wasting away or decrease in size of a part of the body.
Audiometry	Evaluation of an individual's hearing.
Aura	A feeling or sensation that precedes an epileptic seizure.
Auto immunity	The production of antibodies against a person's own tissues.
Automatism; Automatic Behaviour	A condition in which actions are performed without consciousness or purpose; sometimes follows an epileptic fit.
Autonomic Nervous System	A part of the nervous system which is not under voluntary control.
Avascular necrosis	Death of bone tissue due to interruption to its blood supply. The term applies particularly to the head of the femur (the "ball" of the hip joint). It leads to changes which resemble osteoarthritis.
Axilla	The armpit.
Barium Meal or Swallow	X-Ray examination of the upper gastrointestinal tract (ie. gullet, stomach and duodenum) after swallowing a radio-opaque substance to check for ulcers, tumours, and causes of indigestion.

Benign	Not malignant; favourable for recovery; a mild disease.
Bilateral	Relating to both sides of the body.
Blepharospasm	Acute spasm of the muscles around the eye, causing almost complete, involuntary, closure of the eyelids.
Blood pressure	Pressure exerted by blood as it presses against and stretches blood vessels, especially arteries. Hypertension (high blood pressure), if untreated, increases the risk of cerebrovascular disease (stroke). Hypotension (abnormally low blood pressure) causes feelings of lightheadedness and faintness.
Body cavity	A space within the body that contains various organs.
Bone Scan	Procedure in which a radioactive substance is injected and the radiation emitted from bone is measured.
Bronchi	Branches of the respiratory passageway through which air flows in and out of the lungs.
Bronchiectasis	A chronic disorder in which there is loss of the normal tissue and expansion of lung air passages. It causes difficult breathing, coughing, expectoration of pus, and foul breath.
Bronchiolitis	Inflammation of the bronchioles, the smallest airways in the lungs.
Bronchitis	Inflammation of the bronchi.
Bronchodilators	Drugs used in the treatment of asthma which open up the airways in spasm.
Bronchogenic carcinoma	Cancer of the lung.
Bronchopulmonary dysplasmia	Insufficient growth of the lungs, seen in some very pre-term (premature) infants, who may as a result require oxygen therapy.
Bursa	A sac or pouch of fluid located near joints or friction points in the body.
Bursitis	Inflammation of a bursa.
Cachexia	A state of ill health, malnutrition, and wasting.
Calculus	A stone formed within the body (as in gallstones, kidney stones or urinary bladder stones).

Calipers (walking)	An apparatus fixed to a boot at one end and fitting in to the groin at the other end to take the weight of a weak or injured lower limb.
Cancer	A malignant tumour.
Capillary	A microscopic blood vessel through which material such as oxygen, carbon dioxide and nutrients or waste products are exchanged between blood and body tissues.
Carcinogen	Any substance that causes cancer.
Carcinoma	A malignant tumour.
Cardiac arrest	Cessation of an effective heart beat in which the heart is completely stopped or ceases to pump normally.
Cardiology	The study of the heart and diseases associated with it.
Cardiomyopathy	Disease of the heart muscle.
Carpal tunnel syndrome	Compression of the median nerve as it crosses the wrist, causing numbness, pain and tingling in the hand and fingers. It occurs much more commonly in women than in men.
Cartilage	Gristle. A transparent elastic substance of the body. It lines the ends of bones which form joints.
Cataract	Loss of transparency of the lens of the eye which can cause partial or complete blindness.
Catheter	A tube that can be inserted into a body cavity through a canal or into a blood vessel; used to remove fluids, such as urine or blood, and to introduce diagnostic materials or medication.
CAT Scan	Computerized Axial Tomography - A special xray technique which gives a picture of a horizontal slice through the body at various levels.
Cell	The basic structural and functional unit of all organisms capable of performing activities vital to life.
Central Nervous System	That portion of the nervous system that consists of the brain and spinal cord.
Cerebellum	A part of the brain concerned with coordination of movement.
Cerebral hypoxia	Reduced amount of oxygen in the brain; often due to an interruption or reduction in the blood supply to the brain or a reduction in oxygen content of the blood.

Chelating drug	Substance which inactivates certain metals (such as iron) and is used in the treatment of metal poisoning or where there is an excess of the metal in the body.
Chemotherapy	Treatment of malignant diseases by anti-cancer drugs.
Chorea	Involuntary uncoordinated movements.
Chromosome	One of the 46 small bodies in the nucleus of cells which carry genes.
Christmas Disease	A rare disease of blood clotting, similar to haemophilia.
Chronic	Long-term or prolonged; applied to a disease that is not acute.
Cirrhosis	A liver disorder in which the liver cells are destroyed and replaced by scar tissue. Its effects are very variable, ranging from few or no symptoms, to liver failure resulting in coma or death.
Claudication	Limping with pain in legs on walking; relieved by rest. Due to insufficient blood supply to the limb.
Claustrophobia	Fear of enclosed places.
Cleft Palate	Failure of fusion of the lip and roof of the mouth (palate) during development before birth.
Clot	The end of a series of reactions that change liquid blood into a jellylike mass.
Coccyx	The bones at the lower end of the vertebral column.
Cognitive	Relating to understanding and reasoning; logical thought processes.
Colitis	Inflammation of the lining of the large bowel (or colon) and rectum.
Colon	The greater part of the large bowel.
Colostomy	The diversion of faeces through an opening in the colon, creating a surgical opening on to the abdomen.
Coma	Final stage of brain failure in which there is total unresponsiveness.
Computed Tomography (CT) Scan	X-Ray technique that provides a cross-sectional image of any area of the body.
Concussion	Traumatic Injury to the brain that may result in abrupt, temporary loss of consciousness.

Congenital	Present at the time of birth.
Conjunctivitis	Inflammation of the delicate covering of the eyeball.
Constipation	Infrequent or difficult defaecation caused by decreased movements of the gut.
Contralateral	On the opposite side of the body.
Convulsion	Violent, involuntary contraction and jerking of muscles.
Coronary Artery Disease	A condition in which the heart muscle receives inadequate blood due to narrowing or obstruction of the coronary arteries causing angina and heart attacks.
Cutaneous	Relating to the skin.
Cyanosis	Blue or dark purple discolouration of the lips and nails, due to reduced amount of oxygen in blood.
Cyst	A fluid filled space lined by body tissue.
Cystitis	Inflammation of the urinary bladder.
Cystoscopy	Direct visual examination of the urinary tract through the urethra by means of a tube and lens system.
Cytology	The study of cells.
Cytotoxic Drug	Used in malignant disease to destroy cancer cells.
Debility	Weakness in functions or organs of the body. Loss of power.
Decubitus Ulcer	Bedsore; pressure sore.
Defaecation	Discharge of faeces from the body.
Degeneration	A breakdown in structure or function.
Dehydration	Excessive loss of water from the body.
Delusion	A false idea, entirely without foundation.
Dermatology	Medical speciality dealing with diseases of the skin.
Diagnosis	Distinguishing one disease from another or determining the nature of a disease from signs and symptoms by clinical examination and laboratory tests, etc.

Digestion	The mechanical and chemical breakdown of food to simple substances that can be absorbed from the gut into the body.
Diplopia	Double vision.
Disc Disease	Degeneration of the discs which separate the bones of the vertebral column and accompanied by arthritic changes in the bones themselves. (It is a cause of pain in the back.)
Dislocation	Displacement of a bone from a joint.
Diuretic	A drug that increases the volume of urine.
Dorsiflexion	Bending the foot in the direction of its upper surface.
Duodenum	The first part of the small intestine into which the stomach drains.
Dupuytren's contracture	Localised thickening of the tissues of the palm of the hand, causing progressive flexion (bending towards the palm) of one or more fingers. Surgery may be needed to release the thickened tissue.
Dysfunction	Absence of normal function.
Dyslexia	Difficulty in reading or learning to read, accompanied by difficulty in writing and spelling correctly.
Dysmenorrhoea	Painful menstruation.
Dyspepsia	Indigestion.
Dysphagia	Difficulty in swallowing.
Dysphasia	Difficulty in understanding or using language due to brain damage.
Dysplasia	Changes in the size, shape and organization of cells in tissues due to chronic irritation or inflammation.
Dyspnoea	Shortness of breath.
Dyspraxia	Partial loss of ability to perform coordinated movements.
Dystonia	A group of conditions in which there is prolonged muscle contraction affecting one or more parts of the body, resulting in repetitive twisting movements or abnormal postures; it includes such conditions as torticollis [q.v.] and writer's cramp.
Dysuria	Painful urination.
E-test	A chart used for testing vision and visual acuity.

Eczema A skin rash characterized by itching, swelling, blistering, oozing and scaling of the skin.

Electrocardiogram (ECG) A recording of the electrical changes that accompany the beating of the heart. Often used to diagnose heart disease.

Electroencephalogram (EMG) A recording of electrical impulses of the brain to diagnose certain diseases (such as epilepsy).

Electromyography (EMG) Evaluation of the electrical activity of resting and contracting muscle to ascertain causes of muscular weakness, paralysis and involuntary movements of muscles.

Embolism Obstruction or closure of a blood vessel by an embolus [ie. a blood clot; bubble of air, mass of bacteria or other debris].

Emesis Vomiting.

Emphysema Distension or hyperinflation of the air passages due to loss of elasticity. It can accompany chronic respiratory diseases (such as chronic bronchitis), and causes breathlessness.

Endometrium The lining of the womb.

Endoscope An illuminated tube with lenses used to look inside hollow organs (ie. the stomach; urinary bladder).

Enuresis Involuntary passing of urine at night.

Enuretic alarm An apparatus used in the treatment of bed wetting in children. When it occurs an alarm bell rings to waken the child.

Enzyme A substance which can change the speed of chemical reactions. Enzymes are involved in all the metabolic activities which take place within body cells; lack of any particular enzyme may have far-reaching effects on health. A number of congenital metabolic disorders are due to lack of, or ineffectiveness of, a particular enzyme.

Epidemic A disease that occurs above the expected level among individuals in a population.

Epidemiology Medical science concerned with the occurrence and distribution of disease in human populations.

Erythema Skin redness.

Erythrocyte Red blood cell.

Erythropoietin A hormone that stimulates red blood cell production.

Euphoria An exaggerated pleasant feeling of well-being marked by overconfidence and self-assurance which is often not justified by the circumstances.

Exacerbation An increase in the severity of symptoms or of disease.

Exophthalmos Bulging of the eyeball. It may be a symptom of thyrotoxicosis (an overactive thyroid gland).

External Located on or near the surface of the body.

Factors VIII & IX Substances present in blood which are essential for normal blood clotting. Lack of Factor VIII causes haemophilia, and lack of Factor IX, Christmas disease (q.v.).

Febrile Feverish.

Festinating Gait Rapid, short shuffling steps seen in Parkinson's disease.

Fibrillation Involuntary brief twitch of a muscle; also atrial fibrillation - an irregular rhythm of the heart.

Fibrin A protein which forms the basis of a blood clot.

Fibrosing alveolitis A condition in which the lung tissue becomes thickened and inelastic, causing progressive breathlessness on exertion.

Fibrositis Pain and stiffness in muscles which may be due to local inflammation in muscles. It is an example of soft tissue rheumatism.

Finger counting A rough test of vision by holding up fingers and asking the visually impaired person to say how many fingers can be seen.

Fistula An abnormal passage between two organs or between an internal body cavity and the outside (eg. arterio-venous fistula: a connecting passage between an artery and vein).

Flaccid Relaxed, flabby, or soft; lacking muscle tone.

Forearm The part of the upper limb between the elbow and wrist.

Fracture Any break in a bone.

Fragile X Syndrome Inherited disorder characterized by mental retardation, learning difficulties and physical abnormalities.

Frozen Shoulder Pain and stiffness at the shoulder due to damage and inflammation of the soft tissues around the shoulder joint.

Fulminant	Occurring suddenly with great intensity.
Gallbladder	A small pouch that stores bile, located under the liver.
Gangrene	Death and rotting of tissue.
Gastrectomy	Surgical removal of part or all of the stomach.
Gastroenterology	The medical speciality that deals with the structure, function, diagnosis and treatment of diseases of the stomach and intestines.
Gastrointestinal (GI) tract	A continuous tube running from the mouth to(GI) tract the anus. (Also called: Alimentary Canal.)
Gastroscopy	Examination of the interior of the stomach with an illuminated tube and lenses.
Gene	The basic unit of heredity which is present in the chromosome. It carries information which determines the physical and mental make-up of the individual.
Genetics	The study of heredity.
Genitalia	Reproductive organs.
Geriatrics	Branch of medicine devoted to the medical problems and care of elderly persons.
Gilles de la Tourette Syndrome	A rare condition in which affected people have involuntary repetitive twitching movements, and make repeated sudden explosive noises, including the involuntary uttering of swear words.
Glaucoma	An eye disorder in which there is increased pressure in the eye which can lead to impaired vision and blindness.
Glucagon	A hormone which increases the level of glucose in the blood.
Glucose	A simple sugar; the major source of energy for every cell type in the body.
Glycosuria	The presence of glucose in the urine which is usually an abnormal finding.
Goldenhars syndrome	A congenital syndrome involving multiple malformations of the mouth, eyes and ears. The heart, kidneys, or nervous system may be affected.
Gout	A disease in which there is an excessive amount of uric acid in the blood which gets into joints and causes severe inflammation, pain

and swelling.

Gynaecology The study and treatment of disorders of the female reproductive system.

Haematology The study of blood.

Haematoma A swelling filled with blood.

Haematemesis The vomiting of blood.

Haematuria Blood in the urine.

Haemodialysis Filtering of blood by an artificial kidney apparatus that removes waste material from the blood which is returned to the body in cases of kidney failure.

Haemoglobin The protein molecule in red blood cells which carries oxygen.

Haemophilia A familial (inherited) disease characterized by delayed or entire absence of blood clotting.

Haemoptysis Coughing up blood.

Haemorrhage An escape of blood from a ruptured blood vessel.

Haemostasis Arrest of bleeding.

Hallucination A false perception of something that does not really exist. A sensory experience created from within the brain which may be perceived as a smell, or taste, or vision or feeling that has no basis in the external world.

Heart Attack Myocardial Infarction; Coronary Thrombosis.

Heartburn Burning sensation in the gullet due to acid rising up from the stomach.

Heart murmur An abnormal sound due to the flow of blood across heart valves. It may indicate heart disease.

Hemicolectomy Removal of half of the large gut by surgery.

Hemiplegia Paralysis of the upper limb, trunk and lower limb on one side of the body [mild hemiplegia is known as hemiparesis].

Heparin A substance that prevents blood clotting.

Hepatitis Inflammation of the liver due to virus, drugs, or chemical poisons. The effects of hepatitis, their duration, and the eventual outcome

	are very variable depending on the cause of the condition and on the type of hepatitis.
Hernia	A rupture; the protrusion or projection of an organ or part of an organ from its normal position (most commonly a protrusion of a piece of the gut through openings in the groin.)
Herpes	An inflammatory disease of the skin with blistering due to infection by a virus (Herpes Simplex causes "cold sore"; Herpes Zoster causes shingles).
Hiatus Hernia	A protrusion of part of the stomach through the diaphragm into the chest.
Histamine	A naturally occurring substance which causes increased blood flow in blood vessels. It is also involved in allergic reactions and can produce asthma attacks in susceptible people.
HIV Positive	A blood test which indicates that the person has been infected by the HIV virus.
Hodgkin's lymphoma	One of a group of malignant conditions of lymphoid tissue. The prognosis is usually better than for non-Hodgkin's lymphomas: with modern treatment it is potentially curable.
Homeopathy	A system of medicine based upon the principle that "like cures like". Drugs are given which can produce symptoms of the disease to be cured, but they are administered in negligible amounts.
Homeostasis	Automatic self-regulation to maintain the normal or standard state of the body.
Hormone	A chemical substance produced by a body organ and carried by the blood to another organ/tissue which it provokes into activity (eg. the thyroid gland produces thyroxin; the pancreas secretes insulin; and the ovary produces estrogens).
Housemaid's knee	Inflammation of, and fluid formation in a pouch (or bursa) at the front of the knee joint.
Human Immune Deficiency Virus (HIV)	The causative organism in AIDS.
Humerus	The bone of the arm.
Humidifier	An apparatus for maintaining the moisture in the air of a room at any given level.
Hydrocele (also Hydrocoele)	A swelling caused by accumulation of fluid, especially around the testicle.

Hydrocephalus Enlargement of the skull due to an abnormal collection of cerebrospinal fluid in the chambers of the brain. It frequently accompanies Spina Bifida.

Hydrocortisone A hormone produced by the adrenal gland which affects the handling of sugar and protein by the body. It is also an anti-inflammatory substance which is used in treating diseases such as rheumatoid arthritis and bronchial asthma.

Hyperaesthesia Excessive sensitiveness to touch.

Hyperalgesia Excessive sensibility to pain.

Hyperglycaemia Excess of sugar in the blood.

Hypermetropia Long sightedness.

Hypermotility Excessive movement of the gut.

Hyperplasia Excessive formation of normal tissue which increases in size.

Hypertension High blood pressure.

Hyperthyroidism Excessive activity of the thyroid gland.

Hypertrophy An increase in size of a tissue or organ.

Hyperventilation Over-breathing which, by affecting the chemical balance of the blood, can cause transient feelings of lightheadedness or faintness.

Hypnotic A drug producing sleep.

Hypochondria A morbid preoccupation or anxiety about one's health.

Hypoglycaemia A condition in which the blood-sugar level is below normal.

Hypoglycaemic drugs Drugs which lower sugar in the blood. Used in treating some forms of diabetes mellitus.

Hypomania A degree of elation and excitement greater than normal but less than mania.

Hypoplasia Imperfect development of an organ or tissue.

Hypotension An abnormally low blood pressure.

Hypothermia A severe reduction in body temperature.

Hypotonia	Reduced muscle tone.
Hypoxaemia	An insufficient oxygen content in the blood.
Hypoxia	A diminished amount of oxygen in the tissues.
Hysterectomy	Removal of the womb.
Iatrogenic	Brought about by medical or surgical treatment.
Icterus	Jaundice.
Ictus	A sudden fit (post-ictal: following a fit).
Idiocy	Very severe arrested development causing severe mental subnormality.
Idiopathic	Applied to a condition of which the cause in unknown.
Idiosyncrasy	A peculiarity of constitution or temperament.
Ileostomy	An operation to make an opening through the abdomen into the small gut (ileum); through which the intestinal contents can be evacuated.
Illusion	A mistaken perception; believing something to be what it is not.
IMED pump	An automatic pump for delivering fluids at a steady rate.
Immune	Protected against a particular infection or allergy.
Immunity	The resisting power of the body to invading microorganisms.
Immunoglobulin	An antibody.
Immunosuppressive drug	A drug which suppresses the normal immune mechanisms in the body. Used to permit successful organ grafting (as in kidney or heart transplants). Can also be used in the treatment of some cancers.
Imperforate	Without an opening.
Intermittent Claudication	Pain in the muscles of the legs (usually the calves) and limping on walking due to a decreased blood supply to the lower limbs. It is relieved by rest.
Infarct	An area of death (necrosis) in an organ or tissue produced by the blocking of a blood vessel.

Infarction	The formation of an infarct (ie. myocardial infarction: an infarct of the heart muscle following a coronary thrombosis).
Infection	Invasion of the body by organisms which cause disease.
Inflammation	A series of changes in tissues indicating their reaction to injury, whether mechanical, chemical or bacterial. The cardinal signs are: heat, swelling, pain and redness.
Infusion	A slow injection of a fluid, for instance whole blood, into a vein.
Ingestion	The taking in of food and drugs by mouth.
Inhalation	The breathing into the lungs through the nose and mouth of air, gas or vapour.
Inhaler	An apparatus used for administering an inhalation.
Inheritance	The acquisition of qualities and characteristics from parents and ancestors.
Innervation	Nerve supply to a part.
Innocuous	Harmless.
Insight	Mental awareness.
Insulin	A hormone secreted by the pancreas which regulates the handling of sugars and fats by the body. A deficiency in the secretion of this hormone causes diabetes mellitus, in the treatment of which artificially produced insulin is widely used.
Ipsilateral	Occurring on the same side. Applied particularly to paralysis or other symptoms occurring on the same side of the body.
Iritis	Inflammation of the iris, the coloured part of the eye surrounding the pupil.
Iron chelating drug	A compound that binds with iron to assist its removal from the body.
Ischaemia	A deficiency in the blood supply to a part of the body.
Isometric	Having equal dimensions. Used to describe exercises known as "isometric exercises" which is the contraction and relaxation of muscles without producing movement.
(IVP) Intravenous pyelography	An x-ray examination of the kidneys and renal system following the intravenous injection of a radio-opaque dye.

Jacksonian Epilepsy A form of epilepsy in which there are localised convulsive movements.

Jaundice A yellow discolouration of the skin and mucous membranes due to the presence of bile pigment in the blood. Often it is indicative of liver damage.

Jejunostomy The making of an opening into the jejunum (small gut) through the abdominal wall; through which the contents of the small intestine pass.

Jejunum The portion of the small intestine (small gut) from the duodenum to the ileum.

Juxta-articular Near a joint.

Keratitis Inflammation of the cornea.

Ketone An organic compound which is produced by the breakdown of fats in the body.

Ketonuria The presence of ketones in urine. This can be a sign of diabetes mellitus.

Klinefelter's syndrome A chromosomal abnormality affecting 1:1000 males, who are born with an additional X chromosome. It may cause varying degrees of behavioural problems and/or learning difficulties, as well as absent or delayed sexual development.

Korsakov's psychosis A confusional state or dementia due to brain damage in chronic alcoholism.

Kyphoscoliosis An abnormal curvature of the spine in which there is forward and sidewards displacement.

Kyphosis A curvature of the spine causing a hump back.

Labile Unstable.

Labyrinthitis A condition, usually the result of a viral infection, of the labyrinth, which is the part of the inner ear concerned with maintaining balance. It results in vertigo (a spinning sensation) and tinnitus (ringing in the ears), seldom lasting for more than a few weeks.

Lacrimal Relating to tears.

Laparoscopy Viewing of the abdominal cavity by passing an illuminated tube through the abdominal wall.

Laparotomy Incision of the abdominal wall for exploratory purposes.

Laryngectomy Excision of the larynx (voice box) and a section of the trachea (windpipe), usually because of cancer. A permanent stoma (opening) is created at the front of the throat, into which a tube is inserted to enable breathing. Elderly or very debilitated people may require help with cleaning the tube of the sticky mucus which tends to accumulate. Laryngectomy results in total loss of the ability to speak, although in many cases the use of electrically operated vibrator sound can facilitate communication.

Larynx The organ of the voice, situated at the upper end of the wind pipe. It is also known as the voice box. Across it are spread the vocal cords; the vibrations and contractions of which produce changes in the pitch of the voice.

Laser Light Amplification by Stimulated Emission of Radiation. An apparatus producing an extremely concentrated beam of light that can be used to cut various materials. Used in the treatment of cancer, of detached retina, diabetic retinopathy and in the treatment of certain skin conditions.

Lateral Situated at the side of the body.

Leg The lower limb from knee to ankle.

Lesion Injury, wound, or change due to disease in an organ. A local disease condition.

Leukaemia The generic name for a group of malignant diseases of bone marrow and blood forming organs. Individual diseases are classified according to the type of cells involved and the state and maturity of the cells.

Levodopa (L-dopa) A synthetic drug used in the treatment of Parkinsonism.

Liver The large gland situated in the right upper area of the abdominal cavity. Its chief functions are: (1) The secretion of bile, (2) The maintenance of the composition of blood, and (3) the regulation of processes which handle nutrients.

Lobectomy Surgical removal of one lobe (section) of a lung.

Locomotor Related to movement from one place to another.

Lordosis A form of spinal curvature.

Lucid Clear, particularly of the mind.

Lumbago Pain in the lower part of the back.

Lyme disease An infection resulting from a tick bite; in the early stages it may affect the heart or nervous system, and subsequently may cause recurrent attacks of arthritis in one or more joints. In 10% of people the arthritis runs a chronic course with recurrent joint and muscle pains and eventual permanent damage to the affected joints.

Lymph The fluid from the blood which has passed through the small blood vessel wall to supply nutrient to tissue cells.

Lymphocyte A white blood cell formed in the lymphoid tissue. Lymphocytes produce immune bodies (antibodies) to overcome and protect against infection.

Lymphoma Used to denote any malignant condition of the lymphoid tissue. Generally these diseases are classified as either Hodgkin's or non-Hodgkin's lymphomas.

Macrocephalic Possessing an abnormally large head.

Macroscopic Discernable with a naked eye.

Macula A flat spot or discoloured area of the skin; the most sensitive region of the retina.

Magnetic resonance Imaging (MRI) A form of medical imaging which gives computerised pictures of slices through the body at various levels, similar to those obtained by a CAT scan (q.v.).

Malabsorption Inability of the small intestine to absorb certain nutrient substances.

Malaise A feeling of general discomfort and illness.

Malignant A term applied to any disease of a virulent and fatal nature; but often used to describe cancerous tumours or cancer.

Mania Elevation of the mood accompanied by acceleration of thought and action and often by delusions of grandeur.

Marrow The substance contained inside certain bones. Blood cells are made in it.

Melaena The discharge of black faeces stained with blood which has undergone change after bleeding into the gastro intestinal tract.

Melancholia A state of extreme depression.

Meniere's Disease or Syndrome A disease of the inner ear causing attacks of vertigo (sensation of rotation) and tinnitus (ringing in the ears) with progressive deafness.

Meninges The membranes covering the brain and spinal cord.

Meningitis Inflammation of the meninges due to viral or bacterial infection.

Meningomyelocele A protrusion of the spinal cord and meninges through a defect in the vertebral back bone. (See also: Spina bifida.)

Meniscectomy Surgical removal of a cartilage in a knee joint.

Menopause The normal cessation of menstruation usually occurring between the 45th and 50th year of life. The ovaries no longer release eggs and there is an associated hormonal imbalance which may cause symptoms such as night sweats, hot flushes, irritability and depression. The symptoms may be managed by Hormone Replacement Therapy (HRT).

Menorrhagia Excessive menstrual bleeding.

Menstruation The monthly discharge of blood and endometrium (womb lining) from the uterus (womb), starting at the age of puberty and lasting until the menopause.

Metabolism The use of foods by the body following digestion, absorption and circulation to the body cells. Foods are used both as an energy source and, after being broken down chemically during digestion, as basic materials for making complex chemical compounds required by the body.

Metabolite Any product or substance taking part in metabolism.

Metaplasia Abnormal change in the structure of a tissue. May be indicative of malignant change.

Metastasis The transfer of a disease from one part of the body to another through the blood vessels, via the lymph channels or across the body cavity. Most commonly used when referring to secondary deposits of a malignant growth.

Methotrexate A cytotoxic drug that is used to treat various types of malignant diseases.

Microbe A minute living organism, especially one causing disease.

Microcephalic Having an abnormally small head.

Micrognathia Failure of development of the lower jaw, causing a receding chin.

Micro-organism A minute animal or vegetable, particularly a virus, bacterium, a fungus, or a protozoan.

Micturition The act of passing urine.

Migraine Paroxysmal (recurrent) attacks of severe headache, often with nausea, vomiting and visual disturbance.

Milestone One of the "norms" against which the motor, social and psychological development of a child is measured.

Monarticular Referring to one joint only.

Monoplegia Paralysis of one limb or of a single muscle or a group of muscles.

Morbid Diseased, or relating to an abnormal or disordered condition.

Morbidity A figure that shows the susceptibility of a population to certain diseases. Usually shown as the number of cases which occur annually per thousand or other unit of population.

Moribund In a dying condition.

Morphine The principal substance obtained from opium and given mainly to relieve severe pain.

Motor Something that causes movement. (Eg. motor nerve is one of the nerves which conveys an impulse from a nerve centre to a muscle to promote activity.)

MRI Scan Magnetic Resonance Imaging: a form of medical imaging giving computerised pictures of internal organs.

Mucous Relating to or secreting mucus. (Eg. mucous membrane: a membrane that secretes mucus and lines many of the body cavities, particularly those of the respiratory and intestinal tracts.)

Mucoviscidosis Another name for cystic fibrosis or fibocystic disease.

Mucus The viscous secretion of mucous membranes.

Murmur A sound heard on listening to the heart, usually originating in the heart itself and is usually due to the turbulence of blood flow through heart valves. It can be an indicator of underlying heart disease.

Myalgia	Pain in the muscles.
Myasthenia	Muscle weakness.
Myelitis	Inflammation of the spinal cord.
Myelography	X-ray examination of the spinal cord following the insertion of a substance which shows up on x-rays into a space which surrounds the spinal cord.
Myeloid	Resembling bone marrow.
Myeloma	A malignant tumour which arises in the marrow cavity of bones.
Myeloproliferative disorders	A collective term for a group of malignant disorders affecting the blood; the most commonly encountered are various types of myeloid leukaemia.
Myocarditis	Inflammation of the heart muscle.
Myocardium	The muscle tissue of the heart.
Myopathy	Any disease of the muscles.
Myopia	Short sightedness.
Myositis	Inflammation of the muscle.
Myotonia	A state of sustained muscle contraction which the person cannot voluntarily relax.
Myringotomy	Incision of the ear drum to drain fluid from an infected middle ear.
Myxoedema	A condition caused by an underactive thyroid gland. There may be swelling of the face, limbs and hands; dry and rough skin; loss of hair; slow pulse; subnormal temperature; slow metabolism and mental dullness.
Naevus	A birthmark: An area of pigmentation of the skin due to dilated blood vessels.
Narcolepsy	A condition in which there is a sudden uncontrollable desire for sleep.
Narcotic	A drug that produces a state of unconsciousness or unnatural sleep. Narcotic drugs are potent pain killers.
Nausea	Any sensation of sickness with an inclination to vomit.

Nebulizer An apparatus for reducing a liquid to a fine spray.

Necrosis Death of a portion of tissue.

Neonatal Referring to the first month of life.

Neoplasm A new growth; a tumour. It may be malignant or benign.

Nephrectomy Excision of a kidney.

Nephritis Inflammation of the kidneys.

Nephrosis Any disease of the kidney.

Neuralgia A sharp stabbing pain, usually along the course of a nerve, owing to inflammation of the nerve or some other disturbance.

Neurasthenia A condition in which there is much mental and physical fatigue, inability to concentrate, loss of appetite and a failure of memory.

Neuritis Inflammation of a nerve with pain, tenderness and loss of function.

Neurologist One who is an expert in the treatment of diseases of the nervous system.

Neurology The scientific study of the nervous system.

Neurone A nerve cell.

Neuropathy A disease process of nerve degeneration and loss of function.

Nocturia The passing of urine at night.

Non compos mentis (Latin) Applied to a person whose mental state is such that he is unable to manage his own affairs.

Noxious Harmful.

Nucleus The essential part of a cell, governing its nutrition and reproduction, its division being essential for formation of new cells.

Nystagmus An involuntary rapid movement of the eyeball. It may indicate disease of the inner ear or of the central nervous system.

Obese Very fat.

Obsession An idea which persistently recurs to an individual, although he resists it and regards it as being senseless. A compulsive thought.

Occipital Relating to the occiput.

Occiput The back of the head.

Occlusion Closure, applied particularly to alignment of the teeth; blockage of arteries.

Occult Hidden, concealed.

Ocular Relating to the eye.

Oedema An excessive amount of fluid in the body tissues causing swelling.

Oesophagus The canal which extends from the pharynx to the stomach. The gullet.

Olfactory Relating to the sense of smell.

Oncology A scientific study of tumours.

Oophorectomy Removal of an ovary.

Opiate Any medication containing opium.

Optic Relating to vision.

Organic Relating to the organs. (Eg. organic disease: disease of an organ, accompanied by structural changes.)

Organism An individual living being, animal or vegetable.

Orthopaedics The branch of medicine dealing with deformities, injuries and diseases of the bones and joints.

Orthotic Promoting the straightening of a deformed or distorted part.

Os A bone.

Ossicle A small bone.

Osteitis Inflammation of bone.

Osteochondritis Inflammation of bone and cartilage which may cause pain and deformity.

Osteomalacia A disease characterised by painful softening of bones. Due to vitamin D deficiency in adults.

Osteomyelitis Inflammation of a bone due to infection.

Osteosarcoma A malignant bone tumour.

Otolaryngology The scientific study of the ear and the larynx and the diseases affecting them.

Pacemaker An electrical device which stimulates the heart muscle to contract. It consists of an energy source, usually batteries, and electrical circuitry connected to an electrode which is in direct contact with the heart muscle.

Paediatrics The branch of medicine dealing with the care and development of children and the treatment of children's diseases.

Paget's disease A chronic disease of bone leading to dense bone formation with areas of bone rarefaction, which produces bone pain, deformity, enlargement of the skull and possibly consequent deafness.

Palliative Treatment which relieves, but does not cure disease. Often used in reference to treatments for cancer.

Palpation The examination of the organs by touch or pressure of the hand over the part.

Palpitation Rapid and forceful contraction of the heart of which the person is conscious.

Palsy Paralysis.

Pancreas An organ situated behind the stomach which produces hormones (insulin and glucagon) and digestive fluids which drain into the small intestine.

Papilloedema Swelling of the optic nerve at the back of the eye which may indicate an increase of pressure within the skull.

Paraesthesia An abnormal tingling sensation (ie. "pins and needles").

Paralysis Loss of the power of movement of any part, as a result of an interference with the nerve supply.

Paramedical Having some association with the science of practice of medicine.

Paranoia A mental disorder characterised by delusions of persecution.

Paraparesis An incomplete paralysis affecting the lower limbs.

Paraphrenia Schizophrenia occurring for the first time in later life.

Paraplegia Paralysis of the lower extremities and lower trunk. All parts below the point of the injury to the spinal cord are affected. It may be of sudden onset from injury to the cord or may develop slowly as a

result of disease.

Parasite Any animal or vegetable organism living upon or within another from which it derives its nourishment.

Parasympathetic One of two types of nerves responsible for controlling functions which take place at the unconscious level, for example regulating blood pressure.

Parenteral Applied to the introduction to the body of drugs or fluids by routes other than the mouth or rectum, for instance intravenously or subcutaneously.

Paresis Partial paralysis.

Paroxysm A sudden attack of recurrence of a symptom or of a disease. It may also mean convulsion.

Pathogen A parasitic micro-organism such as a virus or a bacterium which can cause disease.

Pathognomonic Specifically characteristic of a disease.

Pathology The branch of medicine concerned with the study of disease processes and mechanisms.

Penicillamine A drug which is used in the treatment of severe rheumatoid arthritis. It is also used in cases of copper and lead poisoning to assist in the elimination of the metals from the body.

Peptic Ulcer An ulcer usually in the stomach or the duodenum, caused by an excess of acid.

Percutaneous Through the skin.

Perfusion The passage of liquid through a tissue or an organ, particularly the passage of blood through the lung tissues.

Peritoneum The lining membrane of the abdominal cavity which also covers some of the abdominal organs.

Peritonitis Inflammation of the peritoneum due to infection.

Permeability The degree to which a fluid can pass from one structure through a wall or membrane into another.

Pernicious Highly destructive; fatal. (eg pernicious anaemia: an anaemia due to lack of absorption of vitamin B12 for the formation of red blood cells which if untreated is fatal.)

Pertussis	Whooping Cough.
Petit mal	Absence seizures. A form of epilepsy common in children and characterised by sudden and brief absences.
Phalanges	The bones of the fingers or toes.
Pharynx	The muscular tube lined with mucous membrane situated at the back of the mouth. It leads to the gullet, and also communicates with the nose and windpipe.
Phenylketonuria	This is an inherited abnormality leading to severe mental deficiency which, if detected early, can be treated by a diet that is low in the substance (aminoacid) called phenylalanine which is an essential constituent of protein.
Phenytoin	An anticonvulsant drug.
Phlebitis	Inflammation of a vein, usually in the leg.
Phobia	An irrational fear produced by a specific situation which the person attempts to avoid.
Photophobia	Intolerance of light.
Photosensitivity	An abnormal degree of sensitivity of the skin to sunlight.
Pituitary	A hormone-secreting gland situated at the base of the brain. It secretes many different types of hormone.
Placebo	An inactive substance which when administered under the impression that it is a drug causes some improvement which cannot be related to any particular drug effect.
Plantar	Relating to the sole of the foot.
Plantar fasciitis	Inflammation of the tissues of the sole of the foot causing chronic pain on walking.
Plasma	The yellow fluid part of the blood.
Platelet	Disc-shaped structures found in blood concerned in the process of clotting. (Also known as a thrombocyte).
Pleurisy	Inflammation of the lining of the lung which causes a sharp pain in the chest on breathing.
Plexus	A network of veins or nerves.

Pneumonectomy	Partial or total removal of a lung.
Pneumonia	Inflammation of the lung which is usually accompanied by fever, coughing, breathlessness and pains in the chest.
Poliomyelitis	This is the full name for the disease known as "polio", which is due to damage to nerves in the spinal cord resulting in paralysis and wasting of muscle groups. It is caused by the polio virus.
Polyarthritis	Inflammation of several joints at the same time, as seen in rheumatoid arthritis.
Polydipsia	Excessive thirst. It may be a symptom of untreated diabetes mellitus.
Polymyalgia Rheumatica	A condition which causes persistent or recurrent aching pain in the muscles, often involving the shoulder or hip region.
Polyuria	Excessive urination; often in conjunction with polydipsia.
Posterior	Towards the back.
Posthumous	Occurring after death.
Postmortem	After death. (Postmortem examination).
Postnatal	Occurring after birth.
Postpartum	Occurring after labour.
Postprandial	Occurring after a meal.
Pott's Fracture	A fracture dislocation of the ankle.
Precancerous	Applying to conditions or structural changes in tissues that may precede cancer.
Prednisolone, Prednisone	Synthetic corticostenoids used in the treatment, of various allergic and rheumatic conditions.
Premenstrual	The days preceding the onset of a "menstrual" period.
Prenatal	Before birth.
Presbycusis	Progressive deafness in old age.
Proctalgia	Pain in the rectum and/or anus (the lower end of the large bowel).
Proctocolectomy	Surgical removal of the rectum and large bowel.

Prognosis	A forecast of the course and duration of a disease.
Proliferation	Rapid multiplication of cells.
Prone	Lying face downward.
Prophylaxis	Measures taken to prevent a disease.
Prostaglandin	One of several hormone substances produced in many body tissues including the brain, lungs, uterus and stomach. They have many different actions and are involved in the process of inflammation.
Prostate	A gland at the base of the bladder in the male which produces fluid which forms part of the semen. It often becomes enlarged after middle age and may require removal.
Prostatectomy	Surgical removal of whole or of part of the prostate gland.
Prosthesis	The fitting of an artificial part to the body, such as artificial limbs, dentures and pace-makers. It is also used to describe artificial valves placed in the heart.
Prostation	A condition of extreme exhaustion.
Protein	One of a group of complex organic nitrogen containing compounds formed from simpler substances known as aminoacids, and occurring in every living cell of animal and vegetable tissue.
Proteinurina	A condition in which protein is present in the urine. It may be an indicator of damage to the kidneys.
Proximal	In anatomy, that part which is nearest to the centre of a body.
Pruritus	Irritation of the skin with itching.
Psoriasis	A chronic skin disease characterised by reddish spots with silvery scales. It is not infectious and the cause is unknown. Sometimes it is associated with arthritis affecting many joints.
Psychiatry	The branch of medicine which deals with mental disorders and their treatment.
Psychogenic	A disorder of psychological origin.
Psychosis	A severe mental illness affecting the whole personality.
Psychosomatic	Relating to the mind and the body.
Psychosomatic	Those illnesses in which emotional factors have a profound

Disorders	influence, including eczema, asthma and ulcerative colitis.
Ptosis	Drooping of the upper eyelid.
Puberty	The period during which the sexual characteristics develop and the reproductive organs become functional.
Puerperium	A period of about six weeks following child birth.
Pulmonary	Relating to the lungs.
Pulse	The local rhythmic expansion of an artery which can be felt with the finger.
Pyrexia	Fever.
Quadriceps	A group of muscles in the front of the thigh.
Quadriplegia (Tetraplegia)	Paralysis of all four limbs.
Radiograph	An x-ray picture.
Radiographer	A person trained to take x-ray pictures.
Radiologist	A doctor specialising in the interpretation of x-rays (radiology).
Radiotherapy	The treatment of disease (usually cancer) by x-rays.
Radius	One of the two forearm bones.
Raynaud's Phenomenon	Intermittent blanching of the fingers and toes, usually precipitated by cold or vibration.
Rectum	The lower part of the large intestine.
Reflex	An automatic response to an outside stimulus. For example, a tendon reflex is jerking of a muscle produced by striking certain tendons, the intensity of the response indicating the presence or absence of neurological disease and its nature.
Rejection of Transplant	The formation of antibodies in the blood which react with the transplanted organ, eventually leading to its destruction.
Renal	Relating to the kidney.
Repetitive strain injury (RSI)	A variety of musculoskeletal disorders, generally affecting muscles or tendons of the upper limbs, neck or back, resulting from repetitive and forceful motions or from activities carried out in awkward postures.

Resection The surgical removal of an organ or part of the body.

Respiration The act of breathing.

Respirator An artificial device used to aid the act of respiration in those who are unable to do this adequately themselves.

Retina The lining at the back of the eye where the image is formed.

Retinopathy Disease of the retina. Most often found in diabetes and high blood pressure, sometimes leading to impairment of vision and blindness.

Rheumatism A general term to describe disorders affecting the joints, muscles, tendons and ligaments.

Rheumatology The branch of medicine concerned with disorders of the joints, muscles, tendons and reflexes.

Rickets A disease of children caused by a lack of vitamin D. Now rarely seen in children, but some elderly people who had the disease in childhood may be left with deformities, particularly of the lower limbs.

Romberg's sign An inability to stand without swaying if the eyes are closed.

Royal Free Disease Another name for myalgic encephalomyelitis.or post-viral fatigue.

Rubella German measles which may cause mental retardation, deafness and other abnormalities in babies whose mothers have contracted the disease in early pregnancy.

Sacroiliac joint The joint between the sacrum and the adjoining part of the pelvis.

Sacrum The bone at the lower end of the back bone forming the back of the pelvis.

Sarcoidosis A disease of unknown cause affecting many parts of the body, but principally the lungs.

Sarcoma A particular type of malignant tumor arising from bone, cartilage, muscle, fat or other related tissues.

Sciatica Pain down the back of the leg, usually caused by pressure on the sciatic nerves by a displaced disc in the back bone.

Scleritis Inflammation of the sclera, the white part of the eyeball.

Scleroderma A disease characterised by thickening and hardening of the skin with consequent impairment of dexterity. It may also affect many other parts of the body, most notably the kidney with the possible development of renal failure.

Scoliosis A curvature of the backbone to either the left or right.

Secretion The production of fluids and hormones by the glands of the body.

Seminoma A malignant tumour of the testicle.

Senescence The process of growing old.

Senility A state of mental and physical deterioration resulting from old age.

Sensory nerves Those nerves responsible for the appreciation of touch, pain, temperature and position.

Sepsis Infection.

Septicaemia Presence of large numbers of bacteria in the blood giving rise to a very severe illness with a high fever.

Shock A condition where the blood pressure falls so low that the blood supply to vital organs is threatened.

Sigmoid colon The part of the large bowel just above the rectum.

Silicosis A lung disease caused by the inhalation of silica particles leading to progressive breathlessness and which occurs in miners, stone masons and quarry workers.

Sjogren's syndrome A syndrome resulting in a combination of dry eyes, dry mouth, enlarged parotid (salivary) glands, and polyarthritis. It is seen in up to 30% of people with rheumatoid arthritis.

Snellen's chart A chart consisting of letters of varying sizes used for testing eyesight.

Soft tissue rheumatism A variety of conditions affecting the tissues such as the muscles, tendons and ligaments which surround joints, but not involving the joints themselves.

Somatic Relating to the body as opposed to the mind.

Spasmodic torticollis See torticollis.

Spastic paralysis A weakness of muscles associated with rigidity and stiffness.

Sphincter A ring of muscle at the outlet to the bowel or bladder whose contraction prevents incontinence.

Spina bifida A developmental abnormality of the spinal cord and back bone leading to weakness and sensory loss in the lower limbs and incontinence.

Spina bifida occulta A very mild form of spinal bifida which does not lead to any disability.

Spirometer An instrument used for measuring lung function.

Spleen An organ found in the upper left part of the abdomen involved with the manufacture and destruction of blood cells.

Spondylolisthesis A sliding forward of one vertebra on another, usually in the lower part of the back bone and possibly causing back pain.

Spondylosis A condition resulting from degeneration of the discs between vertebrae with the formation of bony outgrowths and arthritis of joints between vertebrae. When occurring in the neck it is referred to as cervical spondylosis whilst when occurring in the lower spine is called lumbar spondylosis. It is associated with pain in the affected part of the spine.

Status Asthmaticus A very severe and prolonged attack of asthma.

Status epilepticus A series of epileptic fits during which the person does not regain consciousness between each fit.

Steatorrhoea The presence of excess fat in the stools which causes them to be bulky and offensive. Found when absorption of fats from the bowel is impaired as, for example, in cystic fibrosis.

Stenosis A narrowing. Usually used in relation to the valves of the heart whose narrowing may lead to heart failure. Also applied to the narrowing of an artery (eg. carotid stenosis).

Steroid A particular type of hormone. One specific type, the corticosteroids, are used to treat certain allergic and rheumatological conditions.

Still's disease A form of rheumatoid arthritis affecting children.

Stomach An organ situated in the upper part of the abdomen joining the oesophagus (gullet) to the small intestine.

Stomatitis Inflammation of the mouth.

Strabismus A squint.

Stridor Harsh, noisy breathing caused by partial obstruction of the upper part of the airway.

Stupor A state of semi-consciousness.

Subarachnoid Haemorrhage A bleed into the space surrounding the brain causing a sudden severe headache and sometimes leading to residual effects similar to those of a stroke.

Subdural Haematoma A blood clot beneath one of the membranes surrounding the brain sometimes occurring as a result of minor injury in the elderly which may lead to progressive mental impairment.

Supine Lying on the back with the face upwards.

Surgery The branch of medicine which treats conditions by operative measures.

Sympathetic nerves One of two types of nerves responsible for controlling functions which take place at the unconscious level, for example regulating blood pressure.

Syncope A simple faint or temporary and very brief loss of consciousness.

Synovitis The inflammation of the membrane which lines a joint. Prolonged inflammation will lead to arthritis.

Syringomyelia A progressive condition of the spinal cord leading to weakness of upper and lower limbs and particularly with loss of pain and temperature sensation in the arms.

Systemic Relating to the body as a whole.

Systolic blood pressure The peak of blood pressure caused by pressure contraction of the heart.

T Cell A particular type of blood cell responsible for certain aspects of immunity and whose function may be impaired in conditions such as AIDS.

Tachycardia A rapid heart beat.

Tachypnoea A rapid respiratory rate.

Talipes A congenital deformity of the foot, commonly known as club foot.

Tarsalgia Pain in the foot.

Tendon A small band of fibrous tissue attaching a muscle to a bone.

Tennis elbow A condition characterised by pain at the outer side of the elbow especially when moving it against a resistance.

Tenosynovitis Inflammation of the sheath surrounding a tendon.

Tetraplegia Paralysis of all four limbs (see quadriplegia).

Therapeutics The science of the healing of diseases with drugs and other measures.

Thigh The lower limb from hip to knee.

Thorax The chest.

Thrombocytopenia A reduction in the number of platelets in the blood leading to bleeding which may occur spontaneously or in response to minor knocks. This may occur into the skin causing bruising or a skin rash (purpura). Other common sites of bleeding are from the bowel or urinary tract.

Thrombosis The sudden formation of a clot within an artery leading to a stoppage of blood flow. This commonly occurs in the arteries to the heart leading to a heart attack or in those to the brain leading to a stroke.

Thyroid A gland situated in the front of the neck producing hormones which regulate the body's rate of metabolism.

Thyrotoxicosis Overactivity of the thyroid gland leading to weight loss, rapid pulse, excessive sweating and intolerance of the heat.

Thyroxine The hormone produced by the thyroid gland.

Tibia The shin bone.

Tic A spasmodic twitching of certain muscles, usually of the face.

Tinnitus A ringing, buzzing or roaring sound in the ears.

Tone The degree of tension within a muscle.

Torticollis (Wry-neck) Contraction of one or more of the neck muscles resulting in the turning of the head to one side.

Toxoplasmosis An infection which in the vast majority of cases goes unnoticed or at most produces a mild flu-like illness. People with impaired

	immunity to infection, such as people with AIDS, may be severely affected with involvement of the heart or nervous system. **Congenital toxoplasmosis** affects infants whose mothers become infected during pregnancy. It may result in severe neurological damage incompatible with survival; less severely affected infants who do survive may subsequently develop severe neurological and visual impairments.
Trachea	The wind pipe.
Tracheostomy	An operation to make an opening into the trachea through the neck. May be seen in patients receiving long term artificial respiration. May also be seen in babies with congenital abnormalities of the upper airways to permit normal breathing.
Transient Ischaemic Attack (TIA)	A short lived reduction of blood supply to the brain leading to possible dizziness, weakness and other symptoms, but which last for less than 24 hours.
Transsexual	A person who believes his or her sex is opposite to his or her physical state.
Transvestite	A person who dresses as a member of the opposite sex.
Trauma	A wound or injury.
Tremor	Involuntary muscular activity leading to rhythmic movements of the particular part of the body affected. Commonly occurs in Parkinson's disease leading to considerable difficulties with dexterity.
Triceps	A muscle situated at the back of the arm.
Trigeminal neuralgia	Pain in the face confined to the area of skin supplied by the trigeminal nerve.
Tuberculosis	An infectious disease which may affect many parts of the body, but which most notably causes a long standing infection of the lungs.
Tympanic membrane	The ear drum.
Ulcer	An erosion or loss of continuity of the skin or lining of the mouth, oesophagus, stomach or intestine.
Unilateral	On one side only.
Uraemia	A condition characterised by a high level of urea in the blood, being one of the manifestations of renal failure.

Urea The main end product of protein metabolism which circulates in the blood and is eliminated from the body by the kidneys.

Ureter One of the two long tubes which connect the kidney to the bladder.

Urethra The tube through which urine is discharged from the bladder.

Urticaria Nettle rash. An allergic reaction, sometimes associated with the more serious condition of angio-neurotic oedema, which may cause swelling of the upper airways and lead to difficulty with breathing.

Uterus The womb.

Uveitis Inflammation of the linings of the eyeball.

Vagotomy Surgical cutting of the vagus nerve, a procedure sometimes used in the treatment of peptic ulcer.

Valgus A displacement outwards as in Genu valgum where the person has knock knees with deviation of the lower legs outwards, or Hallux valgus where the big toes are displaced outwards.

Varicose Swollen or dilated, as in varicose veins.

Varus A displacement inwards as in Genu varum where the patient has bow legs with the lower legs deviated inwards.

Vascular Relating to the blood vessels.

Vasculitis Inflammation of a blood vessel. A common pathological feature in a number of rheumatic and multi-system disorders.

Vasovagal attack Simple faint.

Vein A blood vessel carrying blood back from the tissues to the heart and where blood is under low pressure.

Vena cava Either of the two large veins which lead directly into the heart.

Venereal disease Disease contracted through sexual contact.

Ventilator See Respirator.

Ventricle The name given to each of the two large chambers in the heart, the left and right ventricles. In certain cases heart failure may be referred to as left or right ventricular failure. Also the name given to the fluid filled cavities within the brain.

Vertebra One of the 33 small bones which form the spinal column or

	backbone.
Vertigo	The feeling that either oneself or one's surroundings is spinning round. Most frequently associated with disease of the inner ear such as Meniere's disease.
Virology	The study of viruses and the diseases they cause.
Wernicke's Encephalopathy	An acute state of confusion due to vitamin B deficiency, commonly seen in alcoholism.
Whiplash injury	Injury to the soft tissues and sometimes the spinal cord in the neck due to sudden backward jerking movement of the head, commonly seen in road traffic accidents.
von Willebrand's disease	A form of bleeding disorder causing symptoms similar to those of haemophilia.
Wilms' tumour	A malignant tumour of the kidney occurring in young children.
Wolff Parkinson White Syndrome	A congenital abnormality of the mechanism regulating heart function, resulting in paroxysmal tachycardia (bursts of very rapid heart rate).
X Chromosome	The female sex chromosome, each female cell containing 2 of them.
Y Chromosome	The male sex chromosome, each male cell containing one Y and one X chromosome.

NORMAL DEVELOPMENT IN CHILDREN

	VISION AND MANIPULATION	HEARING AND SPEECH	GROSS MOTOR	SOCIAL BEHAVIOUR	FEEDING
BIRTH	- Follow moving objects with eyes. - Range 45 degrees 8 - 10 inches away. - Hands remain closed. (Involuntary grasp reflex).	- When baby is not crying they will respond to loud noises. - When the baby is crying they will quieten to a noise.	- New born babies have no head control. - Head will flop backwards when laid down. - Head is to one side when laid on its tummy and knees under abdomen.	- New born babies spend most of the day sleeping.	
6 WEEKS	- At 6 weeks a baby can focus and follow an object. - They watch their mothers intently, when she speaks.	- May be startled by loud noises.	- Is beginning to gain head control when pulled from lying down to sitting position. - The head no longer flops backwards.	- Will smile at familiar and unfamiliar people. - May begin to vocalise ie respond to speech by making sounds.	
3 MONTHS	- A baby will follow with its eyes a moving toy, that is held in front of them through 180 degrees. - They will hold hands in front of face and observe them. - Holds a rattle momentarily when it is placed in the hand.	- A baby will babble when spoken to.	- When laid on its tummy the baby is able to lift its head up and bear its weight on its forearms. - The head is held up mostly when the baby is supported in a sitting position	- Recognises mother - Squeals with pleasure and becomes excited when given a toy.	- Feeding, winding, and settling at 3 to 4 hourly intervals by day. - To some extent by night are normal requirements of a health baby. - Night feed is usually dropped at this age.
6 TO 8 MONTHS	- Can grasp objects and enjoys playing with hands held in front. - Will drop an object when another is handed to them. - Can follow objects with their eyes and can also reach for them	- Can respond to sound from behind. - Will use their voice to babble. i.e. They will make different tuneful noises such as baba, dada.	- Child is able to sit unsupported. - When held upright can support own weight to some extent. - Can roll over when laid down on the stomach to back, and vice a versa.	- Responsive to familiar people and apprehensive to unfamiliar people. - Will talk using babble to familiar people. - In a safe situation a baby can play on its own.	- Can drink from a cup / finger feed / chew and therefore eat solids.
9 TO 12 MONTHS	- Can reach for and grasp toys and enjoys feeding self with his fingers. - Can bring fingers and thumb together to pick up objects i.e. a piece of string. - Index finger protrudes as the baby goes for the object. - Will respond to simple vision testing eg. Stycar rolling balls.	- The baby is beginning to have meaningful babble. - May have one or two recognisable words. - Will turn on hearing own name.	- Can crawl and can often walk. - Some children will bottom shuffle instead of crawling, often these children are slow to walk than the children who crawl.	- Child is wary of unfamiliar adults. - Can feed self and drink from cup. - Wave bye-bye, plays pat-a-cake and peek-a-boo, and can also play for long periods of time. - Enjoys dropping objects on the floor if there is someone to pick the objects up. - Responds to "NO".	
15 MONTHS	- Builds a tower with two bricks	- Has a lot of jargon speech.	- Can get to standing position without support. - Can creep upstairs.	- Asks for objects by pointing. - Displays negative behaviour. - Begins to tell parent about wet pants.	

NORMAL DEVELOPMENT IN CHILDREN

CONTINUED...	VISION AND MANIPULATION	HEARING AND SPEECH	GROSS MOTOR	SOCIAL BEHAVIOUR	FEEDING
2 YEARS	- Turns pages singly. - Copies a vertical stroke with a pencil with fist as opposed to the tripod grasp of an adult. - Cooperates with a simple vision test. eg. Stycar toy test.	- Obeys four simple commands. eg."Take it to Mummy." - Able to speak in small sentences and uses the words, " I, Me, You. " appropriately.	- Walks backwards in imitation. - Is able to go up and down stairs using two feet per stair.	- Becomes more amenable to adult control. - Often remains dry at night if lifted late in the evenings.	
2 YEARS 6 MONTHS	- Can build a tower of 6 bricks. - Holds pen with hand instead of in a fist.	- Knows his/her full name - Can name one colour - Can name 5 common objects eg. doggie, car.	- Is able to walk on tiptoe when asked.	- Climbs onto the toilet seat. - Attends toilet needs without help, except for wiping.	
3 YEARS	- Cooperates with Stycar vision testing ie matches letters on cards which are shown to him by the examiner. - Develops a tripod grasp of a pencil. - Can build a tower of 8 bricks and can build a bridge with 3 bricks.	- Cooperates with a formal hearing test. i.e. will put pegs in a peg board in response to a quite noise. - Has a wide vocabulary of several hundred words.	- Child is a skilful climber. - Can ride a bike with stabilisers. - Can run, kick, and attempt to catch a ball. - Goes up stairs one foot per step and goes down stairs two steps at a time. - Can jump from the bottom step. - Can stand on one foot for a few seconds.	- Is sociable, friendly and helpful. - Joins in with other children to play. - Can recite rhymes. - Knows own sex. - Is toilet trained by day, and in most cases by night.	
4 TO 5 YEARS	- Is able to cooperate with vision testing. - Is skilful with a pencil and is able to draw recognisable pictures. - Can copy a circle, square, and triangle. - Can write own name. - Read simple words. - "Handedness" exhibits itself at around 4 years.	- Can often participate in a formal hearing test. - Responds to a noise of a known type and volume played to through headphones (Audiometry). - Has a wide vocabulary. - Can sing tunefully.	- Can hop, skip, jump, etc skilfully.	- Can dress, undress, wash, and bathe with supervision.	
6 YEARS	- Copies a diamond. - Can draw an accurate picture of a person usually (mummy or daddy). - Knows right from left. - Can repeat five digits.	- Is able to name the days of the week, and name 4 coins. - Can count to more than 10 objects which are not in a row. - Can cooperate fully with audiometrical testing.	- Is able to ride a two wheeled bicycle.	- Is able to undress, dress, wash and bathe independently.	

NORMAL DEVELOPMENT IN CHILDREN

TABLE XX.2

PRINCIPAL CARE NEEDS : HEALTHY CHILDREN AGED 3 M0NTHS AND TO 18 MONTHS

AGE RANGE **3 TO 8 MONTHS**	- Development of investigative skills and problem solving abilities increase, with mobility skills. - This can put a healthy child at risk of danger. - The level of required supervision to avoid danger is quite considerable for a healthy child.	
AGE RANGE **9 TO 18 MONTHS**	- The need for close supervision and control of the environment between the ages of 12 to 18 months continues. - There is a rapid development of mobility and the associated skills. - As the child becomes more independent in feeding and pay attention requirements will decrease.	