

## 2. PRESENTATION OF DISABILITY

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### 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.