

# PRINCIPLES OF NEUROLOGICAL REHABILITATION

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This article reviews the basic principles that underlie the subspeciality of neurological rehabilitation. Neurological rehabilitation is in many ways different from the other branches of neurology. Rehabilitation is a process of education of the disabled person with the ultimate aim of assisting that individual to cope with family, friends, work, and leisure as independently as possible. It is a process that centrally involves the disabled person in making plans and setting goals that are important and relevant to their own particular circumstances. In other words it is a process that is not done *to* the disabled person but a process that is done *by* the disabled person themselves, but with the guidance, support, and help of a wide range of professionals. Rehabilitation has to go beyond the rather narrow confines of physical disease and needs to deal with the psychological consequences of disability as well as the social milieu in which the disabled person has to function. Thus, a key factor that differentiates rehabilitation from much of neurology is that it is not a process that can be carried out by neurologists alone, but necessarily requires an active partnership with a whole range of health and social service professionals. The key characteristics of the rehabilitation process are summarised in box 1.

## IMPAIRMENT, DISABILITY, AND HANDICAP

These are key concepts that form the basic principles of neurological rehabilitation. The concepts were developed by the World Health Organization in 1980 (table 1). Although the terms have recently been modernised (and the new definitions are discussed below) the three original terms—impairment, disability, and handicap—are so well known and so ingrained in the philosophy of neurological rehabilitation that it is worthwhile discussing the older terms in the first instance.

Impairment is just a descriptive term. It implies nothing about consequence. Examples are a right hemiparesis, left sided sensory loss, or an homonymous hemianopia. However, a right hemiparesis can obviously be relatively mild and lead to virtually no functional consequence, or can be severe and lead to a complete inability to walk. The functional consequence of impairment is the disability. Investigative and diagnostic neurology clearly needs to identify the impairment in order to lead to appropriate investigations and eventual diagnosis. However, neurological rehabilitation goes beyond the impairment and looks at the functional consequence and tries to minimise the impact of the disability on the individual.

Thus, neurological rehabilitation mainly deals with disability. However, the concept of handicap is equally important. Handicap is the description of the social context of the disability. A person with a right hemiparesis, for example, may have a relatively mild weakness but even a limited weakness may have profound social consequences for some people. A young man with such a hemiparesis may, for example, wish to go into the armed forces or be a long distance lorry driver, and both occupations would be closed to him or an existing job may be lost. However, an older man with a similar degree of hemiparesis may have virtually no limitations placed on his lifestyle. Thus, handicap looks beyond the disability into the broader social context, which in turn will often have implications for the goals of the rehabilitation process. Neurological rehabilitation clearly needs to take into account not only the disability but also the particular handicap for the individual, while bearing in mind that some of the social and physical barriers depend on societal attitudes and the physical environment and may be outside the control of the rehabilitation team.

Recently the WHO has produced a new classification, which has less negative connotations. Disability is now termed activity and handicap now termed participation. These definitions are outlined in table 2.

The principles are the same, but the classification now places more emphasis on the individual's abilities rather than disabilities and more emphasis is given to social context. In other words it is a step towards the social model of disability and a step away from the medical model.

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**Box 1: The rehabilitation process**

- ▶ An educational process
- ▶ Central involvement of the disabled person in programme planning
- ▶ Key involvement of family, friends, and colleagues
- ▶ A process that requires clear goals to be set and measured
- ▶ An interdisciplinary process
- ▶ A process based on the concepts of disability (activity) and handicap (participation)

**MEDICAL AND SOCIAL MODELS OF DISABILITY**

Many readers will feel we are in the unnecessary realm of political correctness. However, practitioners in the field of neurological rehabilitation need to be aware of these different constructs of disability. Neurological rehabilitation has come from an “illness” background. It has, at least in the past, been generally carried out by physicians with the support of nurses and therapists and delivered to disabled people. This health and illness perspective of disability is known as the “medical” model. It assumes many things about the nature of disability, which are summarised in box 2.

In general the philosophy of medicine has been to treat and cure, but in rehabilitation these outcomes are unlikely and in the early days of rehabilitation the aim was to normalise as much as possible. Indeed this philosophy is reinforced by the initial definitions of impairment, disability and handicap proposed by the WHO (table 1). Neurological rehabilitation is now moving away from a rigid interpretation of this model and moving towards the fundamental construct of disability that has been proposed for many years by disability lobby groups. That construct is termed the “social” model of disability. The key points of the social model are outlined in box 3.

The fundamental difference between these two models is that proponents of the social model suggest that the person’s impairment is not the cause of the restriction of activity but rather it is the organisation of society that discriminates against the disabled community. The proponents propose that if society would accept and accommodate disabled people, both physically and attitudinally, then disability as a concept would be made redundant.

In the early years of the disability movement and of rehabilitation practice there was a general feeling of antagonism between health professionals on the one side and the disability movement on the other. In recent years individuals working in the field have tended to adopt a rather more helpful middle ground. Most disabled people clearly

**Table 1** Definitions of the WHO’s International Classification of Impairments, Disabilities and Handicaps

Impairment	Any loss or abnormality of psychological, physiological or anatomical structure or function
Disability	Any restriction or lack of activity resulting from an impairment to perform an activity in the manner or in the range considered normal for people of the same age, sex, and culture
Handicap	A disadvantage for a given individual resulting from impairment or disability that limits or prevents the fulfilment of a role that would otherwise be normal for that individual

WHO 1980.

**Box 2 The medical model of disability**

- ▶ Disability is individualised. It is regarded as a disease state that is located within an individual. Thus, the problem and solution may both be found within that individual
- ▶ Disability is a disease state, a deviation from the norm, which inherently necessitates some form of treatment or cure
- ▶ Being disabled a person is regarded inherently as biologically or psychologically inferior to an able bodied person
- ▶ Disability is viewed as a personal tragedy. It assumes the presence of a victim
- ▶ The objective normality state that is assumed by professionals gives them a dominant decision making role

realise that health professionals have an important and central role in assisting the disabled person to minimise their activity restrictions. Obviously this is particularly true in the post-acute setting—for example, after a stroke or traumatic brain injury. Even in longer term disability, such as cerebral palsy or multiple sclerosis, health professionals still have a key role to play in preventing unnecessary complications and advising on appropriate interventions that reduce activity limitations and promote participation in society. On the other hand most health professionals realise that they cannot solve, nor should they try to solve, all the problems associated with disability as many are a function of inappropriate attitudes and barriers in society. There is a realisation that the health professional should act as a supporter and information giver rather than a dictator of treatment. The distinction between these two models is now rather blurred and a more helpful attitude of partnership between disabled people and the rehabilitation professionals is now being achieved in many rehabilitation units and community teams.

**BASIC APPROACHES IN NEUROLOGICAL REHABILITATION**

Rehabilitation is an active and dynamic process through which a disabled person is helped to acquire knowledge and skills in order to maximise their physical, psychological, and social functioning. This process can be conveniently broken down into three key areas:

- ▶ Approaches that reduce disability
- ▶ Approaches designed to acquire new skills and strategies, which will maximise activity
- ▶ Approaches that help to alter the environment, both physical and social, so that a given disability carries with it minimal consequent handicap.

**Table 2** New classifications of the International Classification of Functioning and Disability: ICIDH II

Impairment	The loss or abnormality of a body structure or of a physiological or psychological function
Activity	The nature and extent of functioning at the level of the person. Activities may be limited in nature, duration, and quality
Contextual factors (participation)	Include the features, aspects and attributes of objects, structures, human made organisations, service provision, and agencies in the physical, social, and attitudinal environment in which people live and conduct their lives. Contextual factors include both environmental factors and personal factors

WHO 1998.

**Box 3: Social model of disability**

- ▶ A person's impairment is not the cause of restriction of activity
- ▶ The cause of restriction is the organisation of society
- ▶ Society discriminates against disabled people
- ▶ Attitudinal, sensory, architectural, and economic barriers are equally, if not more, important than health barriers
- ▶ Less emphasis is placed on the involvement of health professionals in the life of a person with disability

Perhaps an example of these three approaches may be useful.

A middle aged man has multiple sclerosis. He has been working quite successfully in the post room of a large factory. He is married with two children and has an active social life. However, he has recently developed increasing problems with walking secondary to a developing paraparesis, complicated by spasticity. In addition he has recently developed problems of urinary frequency and urgency. A neurological rehabilitation programme, using the three basic approaches, could be as follows:

- ▶ Attempts could be made to reduce his disability by appropriate treatment of his spasticity and medication to help control bladder symptoms.
- ▶ He could learn new skills—for example, walking with external support such as a stick, or perhaps using a wheelchair for longer distances, such as from the office car park to his place of work. He may learn new skills to reduce the problems associated with his bladder difficulty, such as intermittent self catheterisation.
- ▶ Approaches could be made to alter his immediate work environment. He may be advised to buy a perching stool so he could support himself while sorting the post. He may need to approach his employer to change or reduce his hours if prolonged periods of standing lead to increased fatigue. At home there may be a need to provide grab-rails in the toilet or other adaptations to the bathroom or kitchen. His wife and family will need to be involved in this process in order to understand his condition and adjust their family lifestyle to cope with his new problems. His wife, for example, may begin to share the driving if problems with spasticity are beginning to interfere with his ability to control the car.

Neurological rehabilitation is not complicated. It is the practical and common sense application of basic principles applied within the framework of a detailed knowledge and understanding of the natural history of a given condition and associated symptoms.

**THE REHABILITATION PROCESS**

There are a number of basic tasks associated with the rehabilitation process:

- ▶ To work in partnership with the disabled person and their family
- ▶ To give accurate information and advice about the nature of the disability, natural history, prognosis, etc
- ▶ To listen to the needs and perceptions of the disabled person and their family
- ▶ To work with other professional colleagues in an interdisciplinary fashion
- ▶ To liaise as necessary with key carers and advocates
- ▶ To assist with the establishment of realistic rehabilitation goals, which are both appropriate to that person's disability and their family, social, and employment needs.

The last point encompasses another fundamental principle of neurological rehabilitation. The process of rehabilitation is set around the establishment of goals. The first goal to be set is the long term strategic aim. For many a long term goal would be returning to a completely normal lifestyle. For others it may simply be to return home and to remain at home with the help of carers. Once a realistic and achievable long term goal has been established then the smaller steps needed to achieve that goal are determined. If, for example, a long term goal is to be independently mobile without the use of aids, then achieving that goal can be broken down into a number of shorter term sub-goals. This process may, for example, start with sitting without support, then standing without support, then walking with the assistance of one person, then walking with aids, and finally the achievement of independent walking.

The goals must be precise. There is no point in setting vague and subjective goals as neither the rehabilitation team nor the disabled person will be able to monitor where they are in the process. A useful mnemonic to remember what the goals should be is SMART:

- ▶ **S**pecific
- ▶ **M**easurable
- ▶ **A**chievable
- ▶ **R**elevant
- ▶ **T**ime limited

The implication of sensible goal setting is that both the disabled person and the rehabilitation team need to know when the goals have been achieved. Thus, it is equally important for each goal to have a valid and reliable outcome measure attached to it. Jeremy Hobart discusses an appropriate range of outcome measures later in this supplement (p iv22). In summary, there are a number of measures that are designed to monitor overall disability and/or quality of life that can be useful for assessing progress towards the final longer term strategic aim. Shorter term sub-goals often need more specific outcome measures. Such specific measures need to be simple and quick. If improvement in mobility is being monitored then a simple, quick, and reliable measure may be timed walking over 10 metres. It is important to remember that any outcome measure used must be specific, valid, and reliable otherwise it is not worth using. It is also worth remembering that while objective measurement is important, subjective opinion of the disabled person with regard to progress towards the goals is equally important. The goal setting process should never be rigid and will often need adjustment and re-evaluation as the individual progresses through rehabilitation.

**THE REHABILITATION TEAM**

Chris Ward discusses the roles and skills of different members of the team later in this supplement (p iv8). However, in summary it is important to emphasise that a key principle of neurological rehabilitation is the close working together of all relevant health professionals. Indeed many neurological rehabilitation teams also need to involve other professionals outside the context of the health service, including those employed by social services or the employment sector. Many teams benefit from the input of a specialist lawyer. The essence of rehabilitation is that individuals go beyond simply working together but blur their own roles and work together in an interdisciplinary fashion. This would mean that the goals are set not discipline by discipline but according to the needs and requirements of the

disabled individual. If, for example, a major goal is for an individual to climb stairs then it is important that the correct techniques are not simply used in the physiotherapy sessions but are also used by nurses and other therapists throughout the rest of the day. A collection of individuals working within their own discipline and setting their own goals does not count as a rehabilitation team.

### WHO IS IT FOR?

There are essentially five categories of people with disabilities.

- (1) People who will make a spontaneous full improvement over a short period of time—for example, people with mild stroke
- (2) People who will improve steadily and may or may not return to pre-morbid function—for example, moderate stroke or traumatic brain injury
- (3) People who will not improve greatly and who can expect a residual level of disability, but in whom some progress is possible—for example, severe stroke or traumatic brain injury
- (4) People who will deteriorate slowly over time—for example, multiple sclerosis or Parkinson's disease
- (5) People who will unfortunately progress steadily and rapidly—for example, motor neurone disease or malignant glioma.

There is now significant evidence that disabled people in categories 2 and 3 are helped by an interdisciplinary rehabilitation process. The evidence in the context of stroke is summarised in the section by Peter Langhorne (p iv18). There is additional, if less compelling, evidence in the context of traumatic brain injury. There is also now emerging evidence of the usefulness of neurological rehabilitation in the context of people in category 4. There are now a number of reports confirming the impact of rehabilitation in, for example, people with multiple sclerosis.

There is clearly less need to involve a neurological rehabilitation team for people in category 1 who are likely to improve spontaneously without assistance. However, such people still need good quality information and advice regarding their condition and possible, albeit minor, consequences—for example, those with mild brain injury or minor stroke. People in category 5 may not benefit in the traditional sense from rehabilitation but will still need symptomatic support. The neurological rehabilitation team has, for example, an important role to play in the management of rapidly progressive motor neurone disease in terms of symptom alleviation. Thus, there are few people with any form of neurological disability who would not benefit from at least some exposure to a team skilled in the basic principles of neurological rehabilitation. Most rehabilitation effort will be directed towards people with recoverable conditions, but the needs of those with longer term problems should not be forgotten.

### HOSPITAL OR COMMUNITY

Traditionally neurological rehabilitation units have been based in hospitals and largely serve the needs of the post-acute disabled population—particularly after stroke or traumatic brain injury. However, there are a number of drivers that are serving to shift the emphasis from hospital into the community. There is increasing pressure on hospital beds with the consequent pressing need to discharge people as quickly as possible from the relatively expensive acute unit.

There is a realisation that many people with neurological disabilities do not enter hospital and as such will largely miss the benefits of a hospital based neurological rehabilitation unit. This is particularly the case for people with cerebral palsy as well as more slowly progressive conditions such as multiple sclerosis and Parkinson's disease. The development, at least in the UK, of a focus on primary care has also served to highlight the need for adequate rehabilitation teams to be based within the community. There are an increasing number of different community based rehabilitation models and examples include early stroke discharge teams and disease specific community teams, such as a multiple sclerosis team, Parkinson's disease team, etc. There are now an increasing number of nurse and therapy practitioners with specialist training in particular disabling conditions. The UK now has about 150 multiple sclerosis nurses and there are two university based specific training programmes. The evidence base for the efficacy of such teams is still thin but nevertheless such studies that do exist show a clear trend for community based teams to be at least as effective as hospital based teams, as well as being cheaper and preferred by the disabled customers. Neurological rehabilitation practitioners should now be prepared to spend at least some of their time working within the community for the longer term support of people with neurological disabilities.

### A SCIENTIFIC BASE

It is regrettable that until recently neurological rehabilitation was based on pragmatism rather than neuroscientific foundation. However, significant developments in neuroscience in recent years are beginning to move neurological rehabilitation on to a firmer scientific foundation. A guiding principle is that neurological rehabilitation should strive to base its procedures and practices on scientific logic. Such a principle is not always achievable at the present time. However, the slow unravelling of the complexities of neural plasticity and neural repair should serve the speciality well in the future. In addition the present and future advances in functional neuroimaging may have an important role to play in rehabilitation. Such techniques may help to characterise predictors of recovery and help monitor the effects of different interventions. Subsets of patients may be identified who are more likely to respond to a particular technique. Many neuroimaging techniques are not yet available to most rehabilitation units, but hopefully the situation will change in coming years.

### CONCLUSION

This section has outlined the basic concepts, principles, and processes of rehabilitation. In summary, it is a process of education and enablement that must involve the disabled person and their family. It is a process that should be conducted through a series of specific goals en route to a long term strategic aim. It has now been demonstrated that it is a process that can produce real benefit in terms of functional improvement, fewer unnecessary complications, and better coordination of services for the disabled person. In the past rehabilitation has been viewed by some as a vague and woolly process—often with justification. Modern rehabilitation is a combination of a precise science while retaining the art of traditional medicine.

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