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INTRODUCTION

The concept of self-management, including active involvement in decisions about care and shared responsibility with professionals has a confirmed place for many individuals living with the consequences of a long-term neurological condition (Department of Health (DoH), 2005b). Self-management not only involves the skills to cope with medical needs, such as dealing with self-catheterization or walking to reduce spasticity and stiffness, but also includes the emotional and social adjustments required by individuals over time. Although there is research on stages of adjustment and the development of self-management skills, this always has to be taken in the context of the nature of the neurological condition, which may be sudden as in the case of a spinal cord injury (see Ch. 4) or unpredictable in the case of multiple sclerosis (MS) (see Ch. 5).

Individuals and their families are often resourceful in the face of the challenges presented to them by their disability and frequently find solutions without the help of clinicians. However, for many individuals, the experience of a new neurological event such as stroke (see Ch. 2) or a changing disability such as MS requires guidance and support from a health professional. Yet the way in which the support is given, could have a profound effect on how successful a person is at being able to self-manage. As rehabilitation professionals, we have the opportunity to enable individuals to take control of their symptoms and develop a range of skills and strategies to live in an optimum way with their condition. We also have the potential to disempower and inhibit individuals’ abilities to develop self-management skills so that they become more reliant on our help and expertise. To facilitate a departure from help and reliance on an ‘expert physiotherapy clinician’ toward a more collaborative approach which will sustain successful self-management is not an easy or straightforward process.

The evidence relating to successful self-management programmes, demonstrates the value of an interactive
process between the health professional and individual with a focus on shared decision-making and problem-solving (Newman et al., 2004). This would suggest that success would not be achieved through such actions of the therapists as:

1. providing information to the individual about their condition in one format with no opportunity to ask questions
2. providing a home exercise programme just before discharge from physiotherapy, with the expectation the individual will transfer the learning into another environment and continue to exercise.

Consequently, planning and developing appropriate programmes requires an appreciation of the many factors that act as barriers to or enablers of behaviour change and self-management. We can learn not only from relevant research trials, but also from the experiences of individuals and patient groups to help inform and develop suitable programmes. So what is self-management and is it in fact new?

SELF-MANAGEMENT: WHAT IS IT AND WHY NOW?

In definitive texts on self-management there are often assertions concerning changing demographics associated with ageing in the developed world. As population death rates decline, more people are likely to be living with the consequences and challenges of a long-term condition (LTC): as such, demand on health care is likely to grow. Sceptics have suggested that the economic pressures associated with large numbers of people living longer and requiring health care drive the advancement and popularity of self-management programmes. In the UK, people with a chronic disease or disability account for one in three of the total population; people with neurological conditions account for 20% of all hospital admissions and such conditions are the third most common reason for seeing a general practitioner (DoH, 2005b). Individuals with neurological conditions will continue to be intensive users of health-care resources and this number is likely to grow, considering the number of neurological conditions that are more prevalent amongst people over 65 years, e.g. stroke.

In the UK, the NHS Improvement Plan (Department of Health, 2004) highlighted the growing concern about the increasing number of people living with a chronic condition and proposed three levels of management. The NHS Long Term Condition Model included at the ‘top level’ case management for people with more complex (including neurological) conditions. A new form of specialist clinician was introduced to deliver case management to those with complex needs. At the second level, the plan offered disease management for those with specific conditions, e.g. those individuals requiring effective medication alongside care. Finally, at the third level, and thought to constitute 60–70% of the overall patient population, are those individuals that could be helped by self-management programmes, such as those using trained lay leaders to deliver generic group-based programmes, e.g. the Expert Patient Programme (EPP) (DoH, 2001).

Defining self-management

Many definitions of self-management reflect both the medical and social aspects of living with and managing a long-term chronic condition. One commonly used definition is that given by Barlow et al. (2002) referring to self-management as:

... an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life, thus, a dynamic and continuous process of self-regulation is established.

Somewhat confusingly, the term ‘self-management’ is often used interchangeably with ‘self-care’. A comprehensive definition of self-care given by the Department of Health (2005a), shows similarities with Barlow’s definition but with a stronger focus on the medical aspects:

The actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet psychological and social needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or accident.

What these definitions both suggest is that self-management means greater responsibility on the part of the person for their own ongoing and, possibly, changing health needs. Self-management is seen as one aspect of the move towards encouraging patients to play a more active role in their own health, and aligns with other health-care policy in the UK, which emphasizes patient-centred care and engagement (Coulter & Ellins, 2006). But for individuals to become engaged in self-management practices it could be argued that there needs to be a greater concordance with the type of treatment being provided by health-care professionals. The transition towards successful self-management may also happen at different time points for each person; physiotherapists will therefore need to be able to assess an individual’s readiness.
to take on more responsibility. This flexibility may be difficult when the amount of treatment and timing is predetermined. More involvement, self-responsibility and shared decision-making may be key components of self-management but, in some cases, organizations and services are unable to adapt and respond to what is needed.

A focused ethnographic study of individuals attending a stroke club revealed that individualized needs were not addressed during the rehabilitation process and that services were insufficient to ease the transition to community living (Sabari et al., 2000). This suggests that therapy services were not adequately preparing individuals for the transition from regular treatment to self-management, a concern echoed by other authors (Cott et al., 2007; Rittman et al., 2004).

Experts on self-management may not fully agree on all its components, but most agree on what it is not. Self-management is not simply providing the information and expecting the patient to get on with it, nor can we expect patients to adjust to a new or changing condition at the same rates or time points. An individual’s involvement in self-management is (a) likely to fluctuate over time and (b) will depend on several factors (for example; the stage of life when a person receives their diagnosis, and knowledge that a neurological condition is only one part of a person’s life). This will doubtless influence how much time, priority and importance a person gives to self-management – indeed, what they can or want to do. People’s response to self-management is therefore unique (Corben & Rosen, 2005).

Self-management has also been defined according to a specified outcome, e.g. practicing specific health behaviours. It may be inhaler management in the case of people with asthma or controlling diet in people with diabetes (Newman et al., 2004). But the specific health behaviours needed to self-manage a neurological condition are more difficult to specify and generalize. This may be one reason why cohorts involved in research on generic self-management programmes rarely include participants with a neurological condition such as stroke.

Kate Lorig, the founder of a generic group-based programme known as the Chronic Disease Self-management Programme (CDSP), described self-management as distinct from medical care and involving the ‘learning and practicing skills necessary to carry an active and emotionally satisfying life in the face of a chronic condition’ (Lorig, 1993). What this definition adds is the aspect of learning, with the unique difference between self-management programmes and educational programmes being the need to facilitate behaviour change through different means. Clearly, much of health policy on self-management shows an emphasis on partnership and empowerment and this approach has been cited as one of the key components of a person-centred health service (DoH, 2000). But it has been argued that if self-management programmes are provided in clinical settings by health professionals, then the balance of power still lays with the professional not the individual (Wilson et al., 2007). It has also been suggested that implicit in many self-management programmes is an assumption that the best regimes are those suggested by a clinician and that the best outcome is achieved through optimum compliance (Kendall & Rogers, 2007).

Do therapists and patients see a good outcome in the same way, and does it always involve the individual adhering to advice and following treatment plans? Maclean et al. (2002) found that stroke patients perceived by health professionals to be highly motivated were more compliant with the aims and expectations of rehabilitation and more likely to understand and follow the advice of professionals. However, some patients perceived to have low motivation described the mixed messages given by therapists in discouraging their individual efforts. This raises some concerns about which patient is doing better and is more likely to learn the skills of self-management; the patient not complying with treatment and trying activities independently or the patient following advice and complying with rehabilitation (Maclean et al., 2002).

If an individual feels obliged to take part in and comply with a specified treatment strategy is this compliance a successful outcome? This could create a contradiction with the new group of self-managers, described as reflexive autonomous individuals and not passively accepting medical advice (Wilson et al., 2007). Against the rather negative predictions of the growing numbers of people living with a LTC likely to need medical care, there is also evidence from a recent survey that the majority of adults living with a LTC are comfortable taking responsibility for their condition (IPsos MORI for Department of Health, 2009). Again, it is worth remembering that many individuals self-manage without the support of a clinician or self-management training:

Lee, a 77-year-old stroke survivor, lives at home with his wife and no longer receives regular physiotherapy. He described his paretic leg as being unpredictable and no longer under his control, but he dealt with this by ‘learning not to panic, and rely so much on my powerful stronger leg’. He achieved this by setting small tasks where the likelihood of success was high ‘giving my leg a chance to succeed’ (Jones, 2004). Self-management strategies in Lee’s case, involve decision-making, setting targets, and reflecting on progress. He explained, ‘Doing more walking at home is my goal, you must have a goal, and have measures which you can check against which are fairly objective, and I do roughly do that, how many yards I have walked each day, and I use note books and diaries to record how I am doing’.

The key to incorporating shared decision-making into rehabilitation involves inviting the individual to participate in the decision-making and the problem-solving, and not asking the individual to comply with an exercise or treatment. One model used an approach in which the
care was a question of gaining insight into the patient decisions rather than the opposite (Zoffman et al., 2008). Ellis-Hill has also highlighted the importance of the shared discourse between the therapist and patient, to facilitate self-discovery and problem-solving on behalf of the patient. In this way, the therapist is acting more as a guide or coach, rather than an expert. Using this model, the balance of power between professionals and patients is recognized. Ellis-Hill and colleagues developed their Life Thread Model (2008), based on narrative theory and focusing on interpersonal relationships. The model includes:

a. endorsing a positive view of self
b. ‘being’ with somebody as well as ‘doing’ things for them
c. seeing acquired disability as a time of transition rather than simply of loss.

Self-management is not new

The paradox of this growing interest in self-management is the knowledge that it is not a new phenomenon. Individuals have always found ways of coping with their chronic condition, showing resourcefulness both at an individual and community level. Sociologists such as Mike Bury and others have highlighted that models of coping with a chronic long-term condition, based on resilience and self-responsibility, have existed for many decades. They also argue that health-care professionals would make a case that they have long promoted self-management (Bury et al., 2005). There are a great many examples of how people with a neurological condition self-manage, not only at a personal level but also at a more collective/societal level. Peer support is one way that people with the same neurological condition can exchange ideas, experiences and gain advice. Peer support can consist of groups held in local communities, such as a stroke club, and there is a growth of online support groups, particularly when the neurological condition is less common and individuals are not readily able to meet. A good example of this is the Virtual Ataxia Group (Table 19.1).

The starting point for many individuals living with a neurological condition may not always be a medical issue, such as impairment. Social isolation, family life, work and adjustment to the changes over time may be a far more important influence on self-management (Kendall & Rogers, 2007). If we are to integrate self-management principles into therapy programmes for people with neurological conditions, then an agreed definition of what self-management is and what it is not is needed first before exploring the key components and specific interventions. Furthermore, as a therapy profession providing a service for patients with many different neurological conditions, should we also question whether our start point always needs to be about health? After stroke, self-management behaviours are often promoted to prevent a second event and reduce risk factors through strategies such as increasing activity. But exercise and access to community groups can be challenging for stroke survivors who wish to adopt a healthier lifestyle (Rimmer et al., 2008). In this way, social isolation from an inaccessible environment may be more of a barrier to successful self-management. The role in the community played by both formal and informal self-help activities, such as stroke clubs, is also a vital aspect of a more collective approach to self-management (Ch’ng et al., 2008). But these groups are often not accessed by individuals with restricted mobility or communication impairments, or minority and ethnic groups, such as populations from Southern Asia (Davidson et al., 2008).

To understand all aspects of self-management, one needs to look beyond the challenges of specific impairments associated with neurological conditions, to consider the interactions between:

- individual health conditions, e.g. stroke
- personal characteristics (such as motivation)
- restrictions posed by the environment and societal barriers, such as inaccessible work conditions, transport and access to leisure facilities.

<table>
<thead>
<tr>
<th>WHO FOR?</th>
<th>WHAT IS IT?</th>
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<tbody>
<tr>
<td>People with hereditary or acquired ataxia</td>
<td>A group for people who have ataxia but may live in rural areas and cannot access local groups. There are chat sessions online, and all members are encouraged to take an active role in the group. Provides peer support and a forum for people with ataxia to exchange ideas, experiences and solutions about living with Ataxia. <a href="http://www.ataxia.org.uk/page.builder/virtual_branch.html">http://www.ataxia.org.uk/page.builder/virtual_branch.html</a></td>
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**INDIVIDUAL RESPONSES TO SELF-MANAGEMENT PROGRAMMES: THEORY AND RESEARCH**

**Understanding responses to neurological disability**

Traditionally, therapists have guided and supported patients to learn and to gain confidence in dealing with their neurological condition. However, the expectation that patients will follow the advice offered, and that increased information and support will lead naturally to
self-management, does not fully take into account motivations, beliefs and other difficulties that might influence how this advice will be incorporated into individuals’ daily lives.

Why is it important to gain more understanding of motivations, fears and beliefs? Before examining some of the theories underpinning self-management programmes, it is worth reviewing some of the findings from qualitative studies that have explored these concepts. Taking the experience of stroke as the main example, it could be argued that confidence and beliefs about self-management will be based on a diverse range of events occurring in the post stroke period. These may be personal experiences as a result of a change in independence and life circumstances, but equally could be shaped by external factors such as the environment and structure of rehabilitation and the nature of interactions with professionals and family (von Koch et al., 1998).

Fear and uncertainty perceived by individuals is also well documented in studies exploring the early poststroke period (Hafsteindóttir & Grypdonk, 1997; Robinson-Smith, 2002). Anxiety about bringing on a second stroke, or feeling out of control, may act as a barrier to setting goals and taking action. The sudden loss of independence and changes in identity associated with acute stroke also heighten individual concerns about potential losses and the restriction of future roles (Bendz, 2003; Faircloth et al., 2004). This early period of instability and uncertainty post stroke may have a profound influence on forming judgements and beliefs about the future. In addition, the high levels of depression and anxiety experienced by stroke survivors may be compounded by these feelings of dependency and loss of control (Hackett et al., 2005). Some of the practices in early stroke care can reinforce feelings of helplessness and dependency which would not be conducive to developing self-management skills (Andrews & Stewart, 1979; von Koch et al., 2000).

Another common theme in the literature is that individuals may not always follow well-defined stages of adjustment after stroke, and personal ‘readiness’ to take on concepts of self-management and self-responsibility may not coincide with the timing of rehabilitation. The perception of ‘recovery’ has been found to be personal to each individual taking into account a range of other factors such as age and previous health status (Faircloth et al., 2004). Some authors prefer to use the term ‘biographical flow’ to describe how individuals experience the stroke event in the context of their everyday lives. Stroke is not necessarily seen as a catastrophe, but part of a person’s ongoing life narrative with many individuals describing an implicit expectation about continuing to do the things that were done before the stroke (Faircloth et al., 2004).

Benchmarking used by individuals to measure their own progress and adjustment to stroke is also a common finding in qualitative research, and the recovery experience is often constructed by individuals in relation to the practical reality of living with a stroke on a daily basis (Dowswell et al., 2000; Gubrium et al., 2003; Jones et al., 2007). The knowledge and understanding of rehabilitation professionals about individual’s incentives and motivations relating to personal goals could also increase the likelihood of developing strategies and confidence to succeed. Higher levels of tenacious goal pursuit and flexible goal adjustment at 5 months has also been found to be a strong predictor of higher levels of quality of life at 12 months post stroke (Darlington et al., 2007).

Stroke is usually a sudden onset event, but with neurological conditions such as MS, the onset is more gradual but potentially less predictable (see Ch. 5). For many, diagnosis is a protracted experience with the challenge of making sense of the long-term implications of living with a changeable chronic condition. Focus groups carried out with people diagnosed with MS for 5 years or more to explore personal narratives and self-management strategies highlighted the key differences between the early and later stage experiences. The need to get a named diagnosis, lack of psychosocial support and concerns about the consequences in lifestyle dominated the early stages, along with stress and fear about the unpredictability and coping with major challenges. Nevertheless, after a period of time, individuals developed more proactive attitudes and strategies, gaining more knowledge about their own disease progression and accessing formal and informal support networks (Malcomson et al., 2008).

What these qualitative studies tell us is that whilst living with a neurological condition, individuals will experience a number of beliefs, emotional responses and barriers that could influence the successful rehabilitation and self-management (see Table 19.2).

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<tr>
<th>Belief/behaviour</th>
<th>Table 19.2 Factors influencing rehabilitation and self-management</th>
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<tr>
<td>Fear and uncertainty about a second event or dependency on others</td>
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<tr>
<td>Worry about unpredictability of disease</td>
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<tr>
<td>Recovery is personal and perceived within a personal narrative</td>
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<tr>
<td>Concerns for the future challenges</td>
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<tr>
<td>Feelings of discontinuity with previous life</td>
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<tr>
<td>Personal benchmarks which may not match therapy goals</td>
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<tr>
<td>Importance of hope and the possibility of further improvement</td>
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(Sabari et al., 2000; Rittman et al., 2004; Jones et al., 2007; Bendz, 2003.)
Social Cognitive Theory and self-efficacy

What then is the best way of helping an individual to learn more about their own beliefs and responses to rehabilitation? Psychological theories provide a framework for understanding human behaviour, and many self-management interventions are now developed on the basis of different theories. The most commonly cited in the development of self-management programmes is Social Cognitive Theory (SCT), in which an individual’s belief in their own capability to produce a change in a specific behaviour (self-efficacy) is said to be critical to the success (Bandura, 1989; Bandura, 1997). Self-efficacy is a construct introduced by Bandura (1977), and has been defined as ‘people’s beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives’ (Bandura, 1994, pp. 71). Self-efficacy beliefs can determine how people feel, think, motivate themselves and behave with regards to their health. For example, self-efficacy influences motivation and health behaviours, by determining the goals people set, how much effort they invest in achieving those goals, and their resilience when faced with difficulties or failure (Dixon et al., 2007). Individuals with strong self-efficacy tend to select challenging goals, and approach difficult tasks as challenges to overcome, rather than as threats to avoid. In the face of failure, such individuals may heighten and sustain their efforts, quickly recover their sense of efficacy, and even attribute failure to insufficient effort or deficient knowledge and skills that can be acquired (Bandura, 1994).

The difference between SCT and other theories is that Bandura provides a clear direction regarding how to influence self-efficacy, which can inform therapeutic interaction and self-management programmes. The construct of self-efficacy also appears to provide resonance with many aspects of sustaining progress and coping with setbacks whilst living with a neurological condition. The information and feedback that an individual obtains from the performance of a task are the sources of self-efficacy.

There are four main sources of self-efficacy (Bandura, 1997):

1. Mastery experiences
2. Vicarious experiences
3. Verbal persuasion
4. Physiological feedback.

Mastery experiences include positive experiences in a task or skill. As people’s experiences of success may improve their self-efficacy, breaking the task into smaller achievable components may be useful, in order to build up and accumulate confidence (van de Laar & van der Bijl, 2001). For people with stroke, this could be gained following accomplishment of a small personal goal through independent effort (Jones et al., 2007). Mastery experiences are said to be the most reliable source of efficacy information (Schwartzer, 1992) and have been targeted in neurological rehabilitation through a variety of methods (Johnston et al., 2007; Kendall et al., 2007, Watkins et al., 2007).

Vicarious experience is gained through the comparison and modelling of others, as it can be beneficial to observe someone perceived to be similar successfully performing the task, e.g. learning from another individual’s experience of the recovery period post stroke. Seeing others’ achievements, especially for individuals who are uncertain of their capabilities to perform certain tasks, may help the observers believe that they also possess capabilities to perform the same tasks (Bandura, 1997; Shapero Sabari et al., 2000).

Verbal persuasion serves to increase an individual’s belief about their personal level of skill using persuasion and verification from a significant other (stroke professional or key family member). However, verbal persuasion needs to be directed in such a way that it enables the individual to interpret the experience of performing the skills as a success (Bandura, 1997).

Physiological feedback is where the efficacy beliefs are formed from feedback produced by an individual’s own physiological state. Self-efficacy may be increased by the interpretation of the individual’s physical and emotional feelings as positive, rather than negative, e.g. walking unaided post stroke without feeling unsteady (Bandura, 1997; Ewart, 1992).

Neurological rehabilitation could provide the opportunity to address a combination of these four sources of self-efficacy and enhance an individual’s potential to self-manage. If there are multiple components of a personal goal, such as walking, individuals are likely to have a number of distinct, interrelated self-efficacy beliefs (Cervone, 2000). Practice to ensure transference of beliefs regarding capability to different situations and settings therefore requires a dynamic cognitive process (Cervone, 2000). However, there may be limited scope for individuals to practice their own personal tasks in some acute-care setting and receive sustained support to build self-efficacy and functional performance beyond a defined few weeks of rehabilitation. The development of effective self-management skills by enhancing self-efficacy is an approach which would need to be started early in the rehabilitation process.

The Stress Coping Model

Another theory used to inform self-management programmes is the Stress Coping Model (Lazarus, 1990), which focuses on the strategies people use to overcome the challenges and stresses of living with a chronic disease. Programmes based on this model usually incorporate the use of cognitive behavioural techniques to encourage individuals to develop more positive and active coping strategies. Passive and avoidant behaviours
(such as evading activity or not taking medication) will usually have detrimental effects on health outcomes, and, as such, it will be important for therapists to recognize and explore unhelpful beliefs and anxieties that might be impeding progress. An example can be taken from cardiac rehabilitation, where self-management programmes involve individuals learning to perceive feelings of breathlessness and raised heart rate as a positive and necessary step towards fitness, as opposed to a negative experience indicative of a possible medical complication (Ewart, 1992).

**The Transtheoretical Model of Behaviour Change and motivational interviewing**

The Transtheoretical Model of Behaviour Change (Prochaska & Velicer, 1997) has been used in a large number of self-management programmes, and makes an assumption that behaviour changes involve movement through a specified number of stages (Serlachius & Sutton, 2009). The likelihood of change is also influenced by factors related to motivation and readiness to change. These include:

1. precontemplation: no intention to take any action
2. contemplation: intends to take action within the next few months
3. preparation: intends to take action within the next few days
4. action: change in behaviour which has been sustained for less than 6 months
5. maintenance: change in behaviour which has been sustained for more than 6 months.

Interventions should match the participant’s stage of change. However, the model has been criticized in recent years because of problems defining the stages, and following suggestions that the stages are not real time periods and are difficult to operationalize. Nonetheless, a technique known as motivational interviewing (MI) based on the Transtheoretical Model of Change has been used successfully in the acute stroke care setting (Watkins et al., 2007). MI uses a counselling technique based on four principles:

1. To express empathy
2. To develop a discrepancy between unhealthy behaviour and patients’ goals
3. To work with resistance by inviting new perspectives
4. To support self-efficacy.

MI requires therapeutic skills of reflective listening, asking open questions, affirming and summarizing (Levensky et al., 2007). By adopting these principles and skills, practitioners focus on encouraging patients to explore their reasons for behaviour change and help them to develop their own strategies to enable this change. The patient is empowered to make their own decisions, thereby maintaining self-efficacy and increasing their confidence in their abilities to make a change (Levensky et al., 2007).

The move away from didactic expert-led treatments for people with neurological conditions to a more collaborative problem-solving approach is as a positive step towards supporting self-management. But the theoretical basis of each approach requires careful consideration. SCT theory is the most commonly used theory, but in practice, it is likely that there is overlap between the different theories and self-management programmes. There are distinct differences though with SCT, for instance, focusing on behaviour change whilst others focus on the more cognitive aspects of living with the chronic condition, such as coping with stress.

**Components of self-management programmes**

It is important to appreciate the theoretical influences that guide the delivery and content of self-management programmes. This enables the variables and outcomes to be defined and tested using the relevant measures.

Key components of self-management programmes often include:

- **Problem-solving**
  This involves the individual deciding on the problem, breaking it down into smaller parts, thinking of various solutions, selecting a course of action, trying out the action or a strategy and evaluating success, or choosing an alternative action if necessary.

- **Target- or goal-setting**
  Involves translating thoughts into actions, or the difference between what people say and what they do and requires a selection of strategies which if successful can provide mastery experiences.

- **Resource utilization**
  This involves making use of what other resources may be available to sustain participation or enable further progress. It could include accessing local self-help groups, seeking expert advice if a problem emerges, using friends or family to support access to services or activities.

- **Collaboration**
  This involves working together with a health-care professional, to decide together on a course of action, or preferred direction to rehabilitation. The therapist and the individual share expertise; a shift from traditional thinking whereby the therapist is always seen as the expert.

- **Knowledge**
  Living with a neurological condition involves a continuous process of learning from new experiences, particularly when the condition can fluctuate and change over time, such as MS. Increased knowledge about the condition, symptoms and treatment is an important aspect of self-management, but should represent a more active process than just gaining knowledge. A key skill is being able to gather, to process and to evaluate the information.
It is worth restating that successful self-management should always involve ‘doing’, and ‘taking action’: whether mobilizing support or finding a new way of doing something, the action is on the part of the individual. Put more simply, if we are to promote self-management as part of rehabilitation, we need to consider ways of individuals discovering their own strengths and difficulties, experimenting and trying out different strategies and activities; inevitably this requires an element of risk taking. If the activities are not achieved, then we need to support the individual to learn to set their target slightly differently or devise an alternative target (Creer & Holroyd, 1997).

The list of components provides some idea of the complexity and range of skills promoted and facilitated through self-management programmes. But if we remember a self-management intervention does not mean simply imparting and providing information, but an active collaborative process, then we can start to understand how a behaviour change may be possible. However, there can be many different interpretations of each process and skill. Consider the following two alternative approaches to goal setting:

**Process A**
1. Goals are discussed between physiotherapist and patient
2. A suitable goal is decided upon and written in the physiotherapy notes
3. Patient works with physiotherapist to achieve goal within a predetermined therapy time (no time is spent independently practicing activities outside of physiotherapy)
4. Patient achieves goal with the help of the physiotherapist
5. ‘Goal achieved’ recorded in the physiotherapy notes.

**Process B**
1. The patient’s story (narrative) is discussed, what do they enjoy doing and what is important to them?
2. A list of long-term goals and hopes is written down (by the patient, if possible)
3. Patient is encouraged to think of what they would like to work on first, what could be something a little smaller, but still meaningful that they would like to do in the next few days
4. A smaller target or goal is written down with a time frame
5. Patient is asked how confident they feel about achieving the goal within the next few days, and if possible confidence is scored using a self-efficacy scale
6. The action needed by the physiotherapist and the patient is agreed upon together after each physiotherapy session, the patient is asked how they feel they are progressing towards their own goal, and asked to rate their confidence
7. Patient records when they have achieved the target and a record of successes is kept with the patient at all times
8. Families are invited to read the targets and progress made.

It is clear that the second process may take more time and skill, but if the key outcome is to enable confidence to self-manage in individuals with a neurological condition such as stroke, then the interaction is not straightforward, and requires time and patience on the part of the physiotherapist.

**SELF-MANAGEMENT PROGRAMMES: THE EVIDENCE BASE FOR STROKE AND PROGRESSIVE NEUROLOGICAL CONDITIONS**

The precise methods of delivery and features of self-management programmes are still subject to debate. The evidence for and against different types of intervention will be reviewed in this section in relation to conditions of sudden onset, such as stroke, and more progressive and unpredictable conditions, such as MS. The development of programmes for the latter has been slower to progress but this may reflect the complexity and range of challenges facing those living with and managing a changing neurological condition. The number of specifically designed self-management programmes for people with chronic diseases has grown over the past two decades. Programmes can be:

- for a generic group or disease-specific
- delivered by health-care professionals or by trained lay leaders
- group-based or individualized.

There have been few self-management programmes designed specifically for individuals with neurological conditions, the exception being stroke-specific programmes (discussed later in the chapter). Reviews comparing different types of interventions mostly focus on diabetes, asthma and arthritis (Newman et al., 2004; Newbold et al., 2006): Table 19.3 provides a brief critique of some of the different approaches.

Currently, health-care professionals lead most disease-specific programmes; lay leaders have tended to be more involved in the delivery of generic chronic disease programmes. Lay- and professional-led programmes show no differences in outcomes, which raises the possibility that favourable outcomes after self-management programmes are more to do with the effects of group participation than leadership. The mechanisms involved or active ingredients of self-management programmes remain uncertain (Newbold et al., 2006).
Self-management and chronic disease

There is an increasing emphasis on self-management as a component of clinical practice and rehabilitation. Arguably, many of the common components of a self-management intervention are included within most comprehensive rehabilitation programmes. However, a list of components advocated for a self-management programme for people with Parkinson’s disease suggested by Doyle Lyons (2003), fails to emphasize the collaborative, shared approach to self-management advocated by most experts in the area and includes the following:

1. Teach participants to observe their behaviour
2. Teach participants to set measureable goals
3. Allow practice of skills and tasks
4. Target self-efficacy
5. Use a group format
6. Include family members and caregivers
7. Integrate with primary health care

8. Teach general problem-solving skills
9. Include disease education

(Doyle Lyons, 2003).

Self-management programmes are clearly distinct from simple patient education or skills training, in that they are designed to encourage people with chronic diseases to take an active part in the management of their own condition. Kate Lorig and researchers at Stanford University are the main pioneers of self-management research and developed what is perhaps the most well-known programme, the CDSP. The programme is a 6-week, lay-led, self-management skills training course for people with generic long-term physical conditions. Overall evaluations suggest improved outcomes and some cost reductions for chronic care following the programmes (Lorig et al., 1999, Lorig et al., 2001). Main outcomes include increase in exercise, improved coping strategies and symptom management, less fatigue, fewer hospital visits and fewer medical consultations at 6 months follow-up, as well as at 1 and 1 years’ follow-up (Lorig et al., 2001).
The CDSP has been adopted in a number of countries, and in England and Wales has been adapted as the EPP (DoH, 2001). Lorig and others argue that the most empowering aspect of CDSP-based courses is that it is not facilitated by a health professional but by a lay volunteer who has a long-term condition themselves (Kennedy et al., 2005). However, the evidence for this claim is limited. In the UK attempts to integrate EPP into the National Health Service (NHS) has also had limited success (Bury & Pink, 2005), possibly due to the lack of engagement by health-care professionals, particularly general practitioners (Kennedy et al., 2005). Furthermore, trials have not provided convincing evidence of the generalizability of the programme, given that men and ethnic groups are greatly under-represented in most studies (Jordan & Osborne, 2007). One reason for this could be that active self-management is such a complex set of skills (Thorne et al., 2003), that generic approaches are unlikely to reach the depth required to develop these skills, particularly in individuals with more complex conditions such as stroke (Davidson, 2005).

Arguably, many key components of programmes such as the CDSP could be adapted for people with neurological conditions and there has been some success with disease-specific self-management initiatives. A self-management programme developed to encourage exercise behaviours for people with mild to moderate MS showed significant improvements in walking speed and quality of life in the study group. Despite the lack of a control group, the authors suggest this model provides evidence of the potential benefits of introducing an earlier self-management intervention for encouraging exercise in people with MS (Hartley, 2009).

**Issues in self-management research**

The main methodological issues associated with self-management research are:

- no explicit theory, and would be hard to replicate
- intervention is not self-management training, but has a more educational focus
- high levels of attrition, particularly from group-based programmes
- some seminal research is questionable; it lacked a control group and samples were self-selecting
- some groups such as those with lower educational level and men tend not to access self-management programmes
- many of the results report short-term benefits, but few studies report long-term outcomes.

Despite these issues, there are a number of positive outcomes from well-designed programmes, particularly those with a clear theoretical framework and well-described components (Marks, 2001).

**Self-management and stroke**

Stroke is, without doubt, under-represented in self-management research compared to chronic diseases such as asthma, arthritis and diabetes (Newman et al., 2004). Interventions such as the EPP do incorporate components common to many stroke rehabilitation programmes, such as goal setting, self-exercising and skills training to cope with set-backs (Newman et al., 2004). However, during stroke rehabilitation, there is evidence that these components are not consistently patient-centred or collaborative (Wressle et al., 1999). Self-management training could provide the forum to develop these skills, but the CDSP group setting may not be suitable for all individuals, particularly those with aphasia or mobility limitations (Wressle et al., 1999).

Moreover, conditions such as stroke have been traditionally viewed as acute events, and much of the focus has been on the front end of care. Although there is evidence of the potential for further functional improvement in the longer term this is coupled with a concern expressed by individuals about the lack of support once the early period of rehabilitation is completed (Kwakkel et al., 2004; Sabari et al., 2000). There is also a noticeable difference in the management post stroke compared to after cardiac events, with a much more coordinated programme of self-management education, and staged rehabilitation available for cardiac patients. This is even more puzzling considering that the causes of stroke mirror those of chronic heart disease and that the controllable risk factors, such as diet, activity and smoking, are identical. If we view stroke more as a chronic disease, it is reasonable to assume that self-management interventions may also be beneficial for individuals post stroke.

Research to evaluate programmes incorporating certain key principles of self-management training for stroke is emerging. A few studies have attempted to adapt the CDSP for stroke, with mixed results. A randomized controlled trial by Kendall et al. (2007) involving 100 people with stroke applied the CDSP (group/lay led) in Australia in an acute stroke setting. The intervention group avoided a decline in function in the first year post stroke, although the intervention failed to impact on self-efficacy and other outcomes such as mood and social participation. A Shanghai version of the CDSP was trialled for participants with various chronic diseases including stroke (Dongbo et al., 2003). The intervention group had significant improvements in weekly exercise, practice of cognitive management, self-efficacy and health status compared to the control group. However, treatment allocation was not concealed at baseline and large numbers were lost to follow-up in both groups. Neither study had long-term follow-up, a common criticism of self-management research (Taylor & Bury, 2007).

MI, based on the transtheoretical model of change (Prochaska & Velicer, 1997), was tested in a single centre
open randomized controlled trial (Watkins et al., 2007). The aim of MI was to develop confidence in ability to adjust and identify realistic personal goals in the acute setting post stroke. The intervention group received up to four sessions of MI, from a randomly allocated therapist, trained by a clinical psychologist who also provided supervision. Subjects received between one and four sessions of MI; the majority of subjects (72%) received four. There were significant changes in mood at 3 months in the intervention group compared with the control group, and protective effect of MI on depression. This was a robust study, but the results were mixed, with no effect on function, and no long-term follow-up, so results may not be sustained.

A self-management workbook designed to modify control cognitions and based on a prototype for post myocardial infarction has more recently been tested with individuals post stroke (Johnston et al., 2007). The intervention group showed a significant difference in recovery from disability at 6 months after discharge from hospital. However, there was a large attrition rate from the intervention group, which could have biased findings. This study showed no change in the cognitive construct known as ‘perceived control’, which is similar to self-efficacy, despite previous findings by the authors. Although another measure of ‘confidence in recovery’ was affected by the intervention, again there was no immediate mediation effect. The authors suggest a change in confidence may produce more long-term value, and could help sustain belief and encourage the initiation of more self-management strategies (Johnston et al., 2007). Considering the criticisms levelled at generic, group-based programmes, there is some scope for developing and testing more individualized self-management interventions for stroke survivors (DoH, 2007). An intervention (‘Bridges’ - a stroke self-management programme) used a workbook based on self-efficacy principles. It incorporates the main sources of self-efficacy (mastery, vicarious experience and feedback), with content informed by qualitative research and contributions from a group of ten stroke survivors (Jones et al., 2007). Pilot work using a multiple-participant, single-subject design demonstrated significant improvement in self-efficacy (measured by the Stroke Self-efficacy Questionnaire) (Jones et al., 2008) and personal control (measured by the Recovery Locus of Control Scale) (Partridge & Johnston, 1989), but no significant changes in activity, participation or mood.

The measurement of self-management

Measuring self-management is not straightforward, as the behaviours that contribute are multifaceted and depend largely on each individual and the challenges of the particular condition. The most important consideration is to define the outcome of interest, for example activity or levels of fatigue, and then find a valid and reliable measure of the target outcome (DeVellis & Blalock, 2009). There are potentially many outcome measurements that can be used to measure self-management and it may not always be possible to gain direct observed evidence of change in target behaviour. Some measures are reported and cannot be directly observed and can include self-report scales that are about testing more factual information, e.g. knowledge of condition, or measurement of a more subjective state such as perceived competency or mood. Further many measures require a degree of cognitive competency, for example recalling past events, or rating one’s own ability in a certain task, for example ‘walk across the room without falling’.

There are specific scales to measure self-management behaviours, and these can be both generic and disease-specific. The Self-Management Behaviours Scale is a generic measure of self-management and was developed by Lorig and colleagues to evaluate the effectiveness of their chronic-disease self-management programme (Lorig et al., 1996). However, it has also been adopted for disease-specific programmes, such as the Arthritis Self-Management Programme (Barlow & Barefoot, 1996). Responses to different items relating to self-management behaviours, such as managing medication and self-exercise, are measured on either a 6-point Likert scale where 0=none or Never and 5=More than 3 hours/week or Always depending on the context of the question asked, or a dichotomous scale. Finally, two items require responses in frequency of self-management behaviour, e.g. Number of times or Total hours in the past 6 weeks, depending on the question asked (Lorig et al., 1996).

The effectiveness of programmes underpinned by Social Cognition Theory, are often measured using change in self-efficacy. However, Bandura supports a model of measurement in which it is suggested that efficacy beliefs should be measured in terms of specific judgements within the chosen area of activity (Bandura, 1997). Therefore, it is important to use a self-efficacy scale that is relevant to the target behaviours and specific to the context of living with the particular chronic condition. Examples of such scales within neurological rehabilitation are the Stroke Self-efficacy Questionnaire (Jones et al., 2008) and the MS Self-efficacy Scale (Airlie et al., 2001).

Overall, there have been some promising results from early studies of self-management programmes in stroke. But the methodological problems are similar to those for other self-management interventions. Further consideration is needed to identify ways of enhancing self-management within normal clinical practice while the evidence base for specific self-management interventions continues to develop. In addition, there needs to be careful consideration of the behaviours targeted by self-management programmes. Outcome measures may need to include both observed and self-report scales in order to capture fully all potential aspects of change.
ENHANCING SELF-MANAGEMENT: WHAT ARE THE SKILLS REQUIRED BY THERAPISTS?

One of the key determinants of success with the delivery of self-management programmes is the skill of the facilitator or trainer (Newman et al., 2004). To understand the factors that contribute to behaviour change, a therapist needs to have an appreciation over and above the biomedical aspects of the neurological condition, and have an in-depth understanding of social and psychological processes. The way in which rehabilitation is structured may also have to change to emphasize a more collaborative approach to include more focus on discursive/problem-solving strategies rather than physical training and recognize that increasing knowledge and skills acquisition may not be enough to sustain confidence and progress in the longer term (Ellis-Hill et al., 2007).

A key component of self-management programmes is shared decision-making and this clearly involves a two-way process. Information given by the health-care professional should be relevant to the decision-making process. Achieving shared decision-making requires time, skill and effort by both the professional and patient. The provision of self-management information can be seen to be a quicker and easier method, and evidence suggests there is a tendency for health-care professionals to fall back on more didactic paternalistic methods if time is limited or constrained by other demands, such as the acute care setting (Bury, 2005).

Hardeman and Mitchie (2009) suggest that ‘in the absence of training, health-care professionals do not usually posses the knowledge and skills to deliver self-management interventions’ (p. 102). Therapists working in neurological rehabilitation will undoubtedly attend a great many post registration courses to enhance their skills and practice. However, there is very little emphasis given to the key communication skills required to effectively support self-management either within usual rehabilitation or delivering specific programmes (Hardeman & Mitchie, 2009). Efforts are being made to define the knowledge, characteristics and skills required for effective self-management training. Hardeman and Mitchie (2009) suggest the following:

- **Knowledge**: not just of the neurological condition; trainers should understand theories and techniques of behaviour change, and how to impart knowledge to enable optimal learning

- **Communication and relationship-building skills**: using simple non-technical language, active listening skills and encouraging interaction. Taking a person-centred collaborative approach rather than a ‘mastery/expert’ role in training. Promoting a trusting relationship through getting to know an individual’s characteristics and life story, tailoring information and feedback to each individual

- **Managing groups**: using different methods to facilitate learning, e.g. working in pairs, and feeding back to larger group, role-play and observing each other. Providing positive leadership, deflecting a negative atmosphere and demonstrating enthusiasm. In addition understanding the needs of the group as a whole and its individuals, dealing with differences and bringing out the best of each individual

- **Specific behaviour change skills**: using key processes, such as goal setting, and exploring beliefs and confidence, such as those described within Bandura’s Social Cognition Theory (Bandura, 1989). Using modelling skills to encourage vicarious learning and support. Introducing a key structure to encourage involvement in goal setting, such as breaking down tasks, developing an action plan, and recording and reflecting on progress.

The growing body of work that has helped to highlight patient needs also highlights the skills needed by professionals to support self-management. A paper published by the Kings Fund in 2005 reviewed patients’ perceptions about managing their own LTC and relevant literature (Corben & Rosen, 2003). Three key themes emerged from interviews with patients about how providers of health care can support self-management in a more effective way:

1. **Good relationships between professionals and patients**
   - Understanding how individuals perceive their condition
   - Listening and identifying main concerns
   - Allowing time for discussion and ensuring care is planned with them, not for them

2. **Clear accessible information and signposting**
   - Providing enough information after initial diagnosis, and support to understand the condition, treatment and services available
   - The use of key workers and peer support to provide support about services, voluntary organizations and benefits

3. **Flexibility in serviced provision**
   - Individuals need different support at different times
   - Having enough time to talk with individuals is important
   - Being able to fit support from professionals with the rest of daily life, e.g. evening groups, etc.
   - Having access to assistive technology to facilitate self-management across different age groups, e.g. online support systems.

In summary, supporting individuals to self-manage may require a change in how therapists currently work in neuro-rehabilitation. In addition to the key skills required to deliver self-management programmes, it is also necessary for therapists to reflect on some of the values that underpin their practice. Common core principles produced by the
Department of Health (2008) may be a good place for therapists and neurorehabilitation teams to examine how they are currently enabling and supporting self-management. These include principles outlined in the document *Common Principles to Support Self-care* (Skills for Health and Skills for Care, 2008) for supporting and enabling individuals to:

- make informed choices
- assess their own needs and develop confidence to self-care
- access appropriate information to manage needs
- develop skills to self-care
- use technology to support self-care
- access support networks, and participate in the planning and development of services
- undertake risk management and risk taking to maximize independence and choice.

Overall, policy and research strongly support the need for health-care professionals working with individuals with long-term conditions to adopt a more collaborative approach. Therapists working in neurorehabilitation should be no different and need to be ready to learn new skills, work in different ways, and challenge practice that is not consistent with these principles:

As Terry, a stroke survivor explained, ‘I mean sometimes physiotherapy it can be a very passive thing, but I enjoyed it the most when I was putting equal into it as well, and I felt we, things were being achieved’.

### Key Points

- The key outcome of many self-management programmes is a positive change in behaviour and better health.
- Self-management centres on the problems identified by the person; the clinician’s role is to support problem-solving and decision-making, to set goals and, most importantly, to take action.
- Self-management is not new, and individuals have always found creative ways of managing problems and living with a chronic condition.
- Self-management includes gaining knowledge, but it also concerns behaviour change and developing strategies to manage life with a chronic disease (Newman, 2004).
- Self-management interventions are fundamentally different from education programmes.
- Self-management will depend on not only personal factors such as beliefs and motivation, but also environmental factors such as access to equipment, groups, etc.
- The skills required by therapists to not only deliver specific self-management interventions, but also embed some of the principles into their current management, should not be underestimated.

### References


