



Multiple sclerosis information

for health and social care professionals

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Self-management

Self-management is about dealing with the impact that a long-term condition has on a person's daily life. The concept of self-management has caused some confusion within clinical practice over many years, and is not always well defined or understood¹.

There are a number of related terms and definitions which may be useful.

Self-management - refers to an individual's ability to take control of their health and effectively manage their chronic illness, with a strong emphasis on self-efficacy. Understanding a patient's attitude to health and knowledge in this context is important for health professionals.

Self-care - traditionally indicated the performance of activities or tasks by the patient or family, which were previously carried out by professionals. Self-care requires knowledge, skills and understanding of a condition and its management². Whilst self-care and self-management are inextricably linked they are not the same.

Self-help - traditionally has been seen as the act of helping or improving oneself without relying on anyone else, it differs from self-management which is undertaken in partnership.

Self-efficacy - has been described as the belief that one is capable of performing in a certain manner to attain certain goals³. The feeling of self worth and competence to intrinsically motivate an individual's self-efficacy relates to a person's ability to have optimistic beliefs, but in contrast to other features of optimism, perceived self-efficacy explicitly refers to one's ability to deal with challenging encounters.

Self-management is a concept now evident in Department of Health initiatives, for example the *Expert patient⁴* and *Supporting people with long term conditions to self-care⁵*. The aim of promoting self-management is to enable patients to help themselves to manage their long-term conditions, whilst working in partnership with the support of services provided by the National Health Service⁶. A more recent report recognises the benefits of self-management⁷ finding that investment in targeted self-management interventions, particularly for people with long-term conditions, can increase people's confidence to manage their health and well-being and improve their quality of life. The cost effectiveness of this strategy has also been explored⁸.

The estimated 100,000 people in the UK who live with multiple sclerosis require specific skills to live life to the full and successfully manage their condition. Equally, health professionals have the responsibility through Quality, Innovation, Productivity and Prevention (QIPP) to promote and support self-management and to reduce the need for unscheduled acute admissions. The Department of Health⁷ recognises the need for a systematic transfer of knowledge and power to patients to empower them to maximise self-management and choice, engage in decision-making and ensure that there is 'no decision about me without me' so that patients are active participants in all decisions about their care.

The concept of self-management began in the 1960s and it was seen as a method of finding better solutions to illness¹. Today self-management is seen as an integral part of the health care system. With the concept of the Expert Patient arising early in the new century, the Department of Health began to endorse the initiative seeking to empower those with chronic health needs, to take control of their own care and recognised that professionals can support and provide expertise to maintain independence⁹.

Benefits of self-management

80-90% of all care for people with long-term conditions is undertaken by the person themselves or their families. This self-management includes eating well, exercising, taking medicines, keeping in good mental health, watching for changes, coping if symptoms get worse and recognising when to seek help from health professionals.

Supporting self-management in MS involves educating people about their condition and care, and motivating people to look after themselves effectively. Self-management support can be seen in two ways: as a portfolio of techniques and tools that help people to choose healthy behavior and a fundamental transforming of the patient caregiver relationship into a collaborative partnership⁹. The very nature of chronic disease management requires a dynamic, positive approach, encouraging patients to move from a 'passive' helpless role to a 'proactive' one¹⁰. Education is central in re-establishing a sense of control over the condition^{11,12}.

Key attributes to self management include:

- self-efficacy
- resource utilisation
- collaborative partnerships with health and social care professionals
- education

Self-management

- goal setting and monitoring
- problem solving and decision-making.

Research has identified that self-management improves health and quality of life, including: reduced pain (despite increasing levels of functional disability); improved mood; reduced visits to the general practitioner; improved levels of self-efficacy. Changes were noticed within one month of self-management intervention and resulted in sustained improvement in the study groups for up to four years post-intervention¹³.

Self-management in multiple sclerosis

In 2009, the Consortium of Multiple Sclerosis Centers¹⁴ issued a white paper analysing patient self-management in multiple sclerosis and offering guidelines for best practices aimed at empowering patients. These include:

- raising awareness among professionals expert in and providing for patients with MS concerning the needs for patient self-management
- formally evaluating the unmet needs in MS, considering both patient and provider perspectives
- encouraging research on a broad range of MS self-management strategies and outcomes, including assessment of the specific components of self-management programs that are most effective for patients with MS, as well as their optimal delivery eg in-person or via telephone, type of leadership, number of sessions
- eliminating any practice barriers to self-management. This should include engaging patients in all aspects of developing and administering interventions, such as implementation, testing and research, dissemination, and sustainability
- developing evidence-based practice.

In MS self-management includes:

- dealing with symptoms and relapses
- making informed choices about medication
- making best use of available resources
- being a partner with health professionals in making decisions about treatment
- living well and accommodation of MS into everyday life.

People who are most likely to successfully self-manage their MS:

- have a good understanding of MS
- manage the impact of MS on physical, emotional, social and working life and are able to make adjustment where necessary
- actively participate in making decisions with health professionals
- adopt healthy lifestyles
- take action.

Generic self-management programmes

The Expert Patients Programme (EPP) is a free six week course for people with chronic or long-term conditions. The course is delivered by trained and accredited tutors, most of whom are themselves living with a long-term health condition.

The EPP aims to give people the confidence to take more responsibility and self-manage their health and to be active participants in the treatment, management and care of their condition. Rather than focusing on health information about specific conditions, the course looks at general topics including healthy eating, dealing with pain and extreme tiredness, relaxation techniques and coping with feelings of depression.

Work carried out by Professor Julie Barlow of Coventry University evaluating the expert patient programme in people with MS found:

- reduced severity of symptoms
- significant decrease in pain
- improved quality of life control and activity
- improved resourcefulness and life satisfaction¹⁵.

Internal evaluation data⁸, self-reported from approximately 1,000 EPP participants, indicates that the programme provides significant numbers of people living with long-term conditions with the confidence and skills to better manage their condition on a daily basis:

- 45% felt more confident that they would not let common symptoms (pain, tiredness, depression and breathlessness) interfere with their lives

- 38% felt that such symptoms were less severe four to six months after completing the course
- 33% felt better prepared for consultations with health professionals.

MS specific self-management programmes

Some examples of self-management courses for people with MS include: Getting to grips with MS, Taking control and fatigue management programmes.

Getting to grips with MS, Taking control

These MS specific courses are designed for people newly diagnosed with MS but could be suitable for a person at any point along the MS trajectory. They cover disease specific education including research in MS, health promotion including nutrition, exercise and physical activity, positive lifestyle adjustments and managing MS in the workplace. The roles of other professionals involved in MS management such as occupational therapists, physiotherapists and psychologists are explored.

A study of a cohort of people with MS undertaking self-management programmes found 82% of participants felt they had been enabled to cope better as a result of the course, 64% felt they ate a better diet and 72% felt enabled to alter their lifestyles as a response to MS¹¹.

Fatigue management

Fatigue is experienced by 70-90% of people with multiple sclerosis and can have a major negative impact on people's lives. As efficacy of pharmaceutical treatment is modest, fatigue management strategies play a vital role. These include avoiding the build up of fatigue and conserving energy. Fatigue management education delivered in a face to face format in community settings has been found to significantly reduce impact of fatigue on daily life, improve quality of life and increase self-efficacy in randomised trials¹⁶. Other ways of delivering the course such as by teleconference were also successful¹⁷.

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MS Trust resources

MS and me – a self-management guide to living with MS
At work with MS – managing life and work
Living with fatigue

Diet factsheet

Move it for MS – DVD

Exercises on the web
www.mstrust.org.uk/exercises
Stay active
www.mstrust.org.uk/stayactive
StayingSmart
www.stayingsmart.org.uk



We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

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The MS Trust offers a wide range of publications, including a newsletter for health and social care professionals Way Ahead and the MS Information Update, which provides an ongoing update on research and developments in MS management.

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