

## Self-management issues

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Treatment of MS is complex and often involves many health care professionals including neurologists, urologists, MS nurses, family doctors, psychologists, and physiotherapists. This type of care is called the "medical model". The medical model aims to provide medically-based interventions such as medications, equipment and exercises. Because MS is often unpredictable, it is also important that people with MS acquire the knowledge of themselves and their disease to be able manage their everyday lives.

Having the confidence and skills to coordinate all the factors that affect one's health is the foundation of self-management. In studies that have tried to understand healthy ageing with MS, some older people have explained that it took them almost 10 years to understand their MS. However, once they gained the confidence in how to predict and manage their MS symptoms, such as fatigue or pain, they were able to cope better and focus on the other parts of their lives that

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were important to them – being parents, grandparents and professionals. Several wished that they could have learned about their MS and gained the confidence earlier.

Self-management focuses on the fact that knowledge of the disease, understanding of their emotions and their role in the family and society will help people with MS increase their overall quality of life. Having control and employing self-management skills empowers and provides optimism. People who are attentive and have good self-management skills may also be able to detect new symptoms or symptoms that are not due to MS. For example, someone with MS may notice a change in their bladder habits. Using self-management strategies they may detect that the change is not typical for them, and may bring it to the notice of their nurse or doctor.

### **The ingredients of self-management**

Self-management is a concept that was first developed to help people manage living with chronic conditions such as arthritis, pain and diabetes. Some of the messages may be useful in MS. One model of self-management describes how the task of self-management is three-fold in nature:

1. managing the medical symptoms; for example, regularly taking medicines
2. managing new life roles; for example, adapting to change and creating new activities with friends and family
3. managing emotions; for example, recognising stress and frustration and using techniques to manage them, such as deep breathing or time away.

This model outlines six fundamental skills that are used during self-management:

#### **Problem solving**

This involves identifying the problem, determining potential ways to solve the problem and then choosing the best solution. For example, someone may find that standing and cooking meals is very taxing. Using problem-solving techniques, they

would propose and then try out some ideas, such as cooking two meals at a time, testing simple recipes or eating out on certain days of the week.

#### **Decision making**

This involves determining top priorities and then deciding what needs to be done to manage day-to-day activities. For example, when faced with a very busy day, a person may make a list of activities in order of priority – want to do and need to do – then postpone some that are low priority.

#### **Using resources**

This involves organising oneself to use available resources as efficiently as possible. A person may decide to cluster similar chores together to save time, money and energy. For example in order to get more exercise, they may walk to the grocery store but get a bus back. They may also set up some tasks at home such as using online banking instead of travelling to the bank.

#### **Communicating with health care providers**

This is a very important aspect of self-management. In one study examining the keys to healthy ageing with MS, older people with MS explained that it was more helpful when they engaged in a two-way conversation with health providers rather than simply being told what to do. Being prepared for medical visits, using a journal to keep track of issues and recording the outcome of the visits helps people to take ownership of their health.

#### **Taking action**

Often, taking action is the most difficult step. For example, somebody may say “I intend to eat better”, however, this is not an action. After finding out how their diet could be improved and deciding to improve it, they then need to develop new habits. Dropping old habits and replacing them with new ones is a challenge! They may need to routinely participate in the same, new behaviour in order to make it a habit.

#### **Self-tailoring**

This means a person modifying things around them to suit their own needs and the resources available. For example, sleep is very important but

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a person may have to adapt their sleep to manage fatigue, to care for a baby or to work late. They would then try to arrange a time to get some extra sleep when it is convenient. Using self-tailoring, they can propose several ways to make the timing fit their schedule and check those modifications with their nurse or doctor.

**‘Being prepared for medical visits, using a journal to keep track of issues and recording the outcome of the visits helps people to take ownership of their health’**

### **Is self-management learned or innate?**

change – for example discomfort in an area that is not usually bothersome – determine the best course of action and follow through with the action. However these steps can also be learned. There are self-management courses and resources that can teach people to be more mindful (see list at the end of this article).

### **What can get in the way of self-management?**

Effective self-management can be a challenging process that may involve overcoming a combination of different obstacles.

#### **Denial**

Ignoring a change in health or a troubling situation can get in the way of a person with MS taking steps to manage the situation. If they use the self-management techniques described above, they should analyse the problem, plan a course of action and take steps to stay healthy. Delaying action extends the time it takes to find a solution.

#### **Self-defeating thought**

Our thoughts are connected to our behaviours. Therefore an unhelpful thought will lead to an unhelpful behaviour. For example, someone may focus on a single negative detail, dwell on it

exclusively and ignore all the other aspects that have been positive. Another example of self-defeating thoughts are “should” statements. This is when someone tells themselves that things “should” be the way they hoped or expected them to be and then feel hopeless or angry if they are not.

### **Worry rather than reflection**

Thinking about health and other issues does not mean brooding over them. Anyone concerned about their health must be attentive. Using self-management, a person takes steps beyond just worrying: they reflect on the symptom, recognise patterns, understand limitations and plan alternatives.

### **Managing other health problems while ageing with MS**

Many health conditions such as cancer, heart disease and osteoporosis are more common among older people. Prevention and management of other health conditions is important for everyone but it is especially important for people with a disease like MS. Routine screening for cancers such as breast cancer and colon cancer and attending to unusual symptoms is important. In fact, in one study of older people with MS, participants explained that they were more concerned about their other health conditions than their MS. Using self-management techniques prepares people to identify issues and take action to maintain good health.

Sometimes when we discuss health conditions, we focus on the physical conditions and ignore mental health. Attending to mental health as well as physical health is important. Self-management techniques can be used to note changes in sleeping or eating habits and reduced energy levels, as well as mood changes, especially any feelings such as hopelessness. Having a conversation with a doctor or nurse can often help too.

### **Conclusion**

In summary, self-management is part of an overall

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effective long-term management plan that includes health care providers, which aims to help people with MS improve and maintain their health and quality of life. Taking charge does not mean that they become their own doctor. It means that because they are in a unique position as the expert in their own experience of MS, they become a partner, rather than just a recipient, in their health care.

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To download the full issue of *MS in focus*, go to <http://www.msif.org/living-with-ms/ms-in-focus-magazine/>

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### Useful internet resources

#### Websites

<http://patienteducation.stanford.edu/research/> (self-management checklists and questionnaires)

<https://bc.selfmanage.org/onlinebc/hl/hlMain>  
(Online Chronic Disease Self-Management Program)

<http://selfmanagementuk.org/what-self-management> (Self-Management UK)

<http://www.mstrust.org.uk/information/publications/msandme/> (A self-management guide to living with Multiple Sclerosis)

<http://www.nationalmssociety.org/Living-Well-With-MS/Health-Wellness> (Living Well with MS/ Health and Wellness)

#### Mobile apps

Multiple Sclerosis Self-Care Manager  
My Action Planner App