

MS and me - not just waffle!

The development of a self-management guide to living with MS



MS nurse Nikki Embrey is passionate about supporting people with MS to gain the skills needed to successfully manage the condition. One group of people who attended Nikki's course on self-management wanted to share their experiences and spread the word about how self-management techniques have helped them to better cope with the challenges of living with MS.

The group's conclusion - "We wanted action - not just waffle." The result is the MS Trust's new book *MS and me - a self-management guide to living with MS*.

What is self-management?

Nikki Embrey, MS Specialist Nurse, University Hospital North Staffordshire

Living effectively with MS means using all the resources available. Some of those will be internal, like setting goals, and some of them will be external such as finding information. The term often used for this is self-management

"Self-management can enable you to control the things you can control and better deal with the things you can't" *MS and me*

Self-management is recognised as important in today's health care system. The Expert Patients Programme (EPP) is available for people with any long-term condition and there are Getting to Grips courses for people living with MS. These courses aim to improve confidence so that people can become active in managing their MS and the effects it may have on their lives.

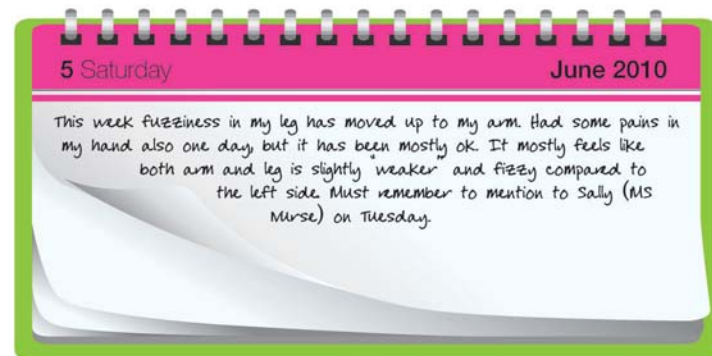
Studies have shown that people who are most likely to successfully self-manage their MS:

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

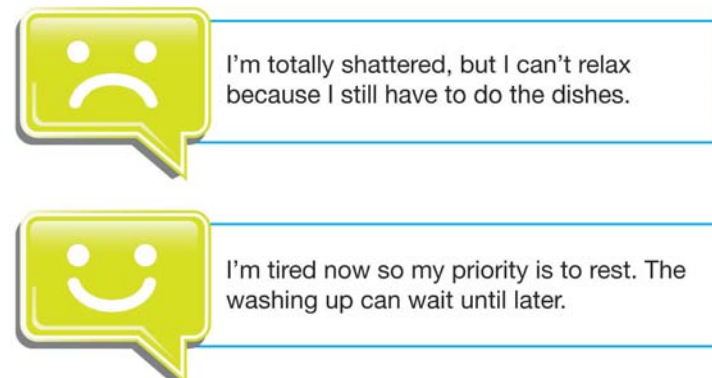
"The very nature of MS requires a dynamic and positive approach: moving from a passive role to a proactive one - learning to take the lead in living with MS and the changes it brings." Liz

Self-management is focused on the individual. This means that, as someone with MS, you are vital to managing your own condition. However this does not mean 'going it alone' but working in partnership with health professionals and with the support of friends and family.

Self-management techniques offer ways to achieve this. For example keeping an MS diary can help you to recognise what might make a symptom worse and remind you of questions to ask your MS nurse or GP.



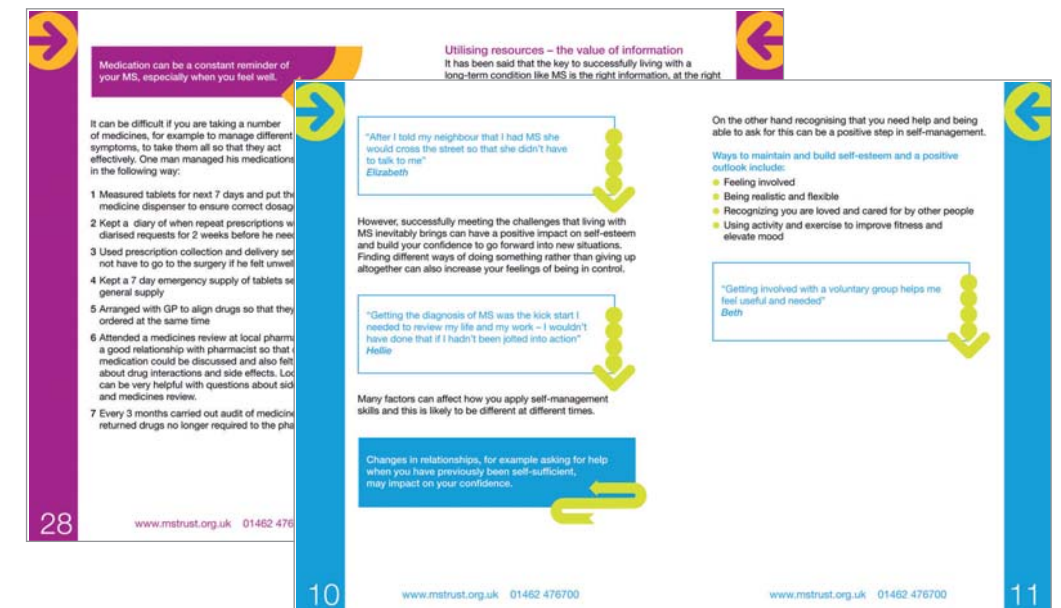
Problem solving techniques can break down what looks like an insurmountable difficulty into manageable pieces, and reframing situations can help you to look at things in a different way.



MS and me aims to support you to gain the skills and confidence that will enable you to make the treatment and lifestyle choices that are right for you.

How MS and me was developed

Carole Chance, Sandra Evans and Liz Gumbley are people with MS who were involved in putting the book together



We knew how important self-management was to us and felt we wanted to share this with others - to provide them with the information we had found useful. We decided we wanted a really accessible self-management guide without too much jargon and felt it was important that it came directly from people who had MS and experience of managing their MS successfully.

Everyone's ideas and experiences of self-management were very different. But eventually we recognised that ultimately self-management means being able to adapt, to solve problems, to make decisions and adopt healthy choices. We agreed that the book needed to feature these elements:

- **Finding and using resources** - information is now more readily available with new ways being designed to help people find appropriate resources to self-manage.
- **Developing partnerships with health professionals** - participation and information sharing are key elements of self-management - working together toward shared goals driven by the person with MS.
- **Solving problems and making decisions** - important skills based upon having the information or knowledge to find solutions to existing and potential problems.
- **Setting goals and monitoring MS** - setting goals helps when monitoring progress. A self-management diary is helpful and encourages better communication with health care professionals.

We wanted it to be useful to people whether they had just been diagnosed or had been living with MS for many years.

"When I was first diagnosed, my thoughts about self-management were very different to now. Initially a feeling of 'why me?' and emotions like fear, anger, depression, hate, and others all came to mind. Now I do feel so much better, I feel that now I am in control, I can influence my health"

Towards the final stages of developing the book we realised that we were all aware of the strategies for self-management, but were not always putting them to the best use. It was interesting to discover that the skills we use in our daily lives - planning, setting goals, etc - were the same skills that we could be using to manage our MS.

The process of developing this book was very empowering, feeling that our experiences as people with MS were valued and that our opinion was actively sought. Knowing that we could help others manage their own condition was very satisfying.

We are excited about the launch of *MS and me* and hope others will benefit from the publication.

Order *MS and me* on the back page or visit www.mstrust.org.uk/publications