



Multiple Sclerosis Society

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Coping when somebody close to you has MS

A booklet for partners,
relatives or friends

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This information is the result of
MS Society-funded research at:

KING'S
College
LONDON

and

Southampton
UNIVERSITY OF

About this manual

- It was written to accompany *Supportive Adjustment for Multiple Sclerosis (saMS) – an eight-week CBT programme manual*.
- It was created as part of an MS Society-funded research trial run by the University of Southampton and King's College London.
- You can download this and the manual free of charge from www.mssociety.org.uk

MS Society research

The MS Society funds a programme of independent research that has revolutionised the diagnosis and treatment of MS over the past 25 years. This has helped establish the UK's global reputation in this area.

The Society's research agenda is led by people with MS, working alongside independent panels of experts. We continue to search out advances in symptom management, developing better services, identifying the causes of MS as well as breaking new ground for better treatments. Our ultimate aim is a world free of MS.

The MS Society has invested over £133 million in MS research since 1956, and it will continue to be a key priority in our aim to beat MS.

Find out more at www.mssociety.org.uk/research or call 020 8438 0799 (weekdays 9am-4pm).

Authors' INTRODUCTION

This booklet is written for partners, relatives or friends of someone with MS who is using the *Supportive Adjustment for Multiple Sclerosis (saMS)* manual.

The saMS manual can help a trained therapist work through an eight-week cognitive behavioural therapy (CBT) programme with the person with MS.

The programme can help the person with MS find ways to make it easier to adjust to living with MS and have a better quality of life. They might find it helpful to talk to you about what the therapy sessions are all about, get you involved, and show you some of the materials they are covering.

'Support people' like you are very important in helping people with MS to adjust to living with the disease. But as someone close to them, you might also encounter many challenging issues and feel that you don't get enough support or advice. This booklet is designed to illustrate some of the common difficulties that you might encounter and provide some strategies or suggestions for dealing with them.

Throughout this booklet we give examples of people's experiences. These are taken from a series of interviews we conducted with 30 people with MS and 15 of their partners/ spouses to find out what difficulties they encountered and what they found helpful and unhelpful when dealing with these issues.

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Dealing with feeling helpless

A diagnosis of MS, and the realisation of what this means, often generates feelings of helplessness in partners and those close to people with MS. Jenny provides a good example of these feelings:

“I feel a bit lost at times, because you can't help someone suffering with this disease, it's impossible, it's out of your hands and you feel sort of... like... I don't know, helpless, frustrated, and very angry.”

Men in particular seem to struggle with feeling out of control, as Gary describes:

“As the actual man, I am supposed to protect, to lay down my life, and do whatever it takes to protect my partner, my wife. But in this situation there is nothing you can do. It's very difficult to describe, you feel like you're just powerless to actually do anything. It is like the control has been taken from you. So it's emasculating really, it's difficult to describe more than that..”

It's not surprising that MS provokes such strong feelings of helplessness – it is unpredictable and currently incurable and it is distressing to see somebody you care about having to deal with this. There is no magic wand available for you to put things back to how they were before. But there are ways to manage symptoms, limitations and emotional responses related to MS. Your partner or friend will look at these in his/ her sessions with the nurse. Also, from what the people with MS we interviewed told us, there is a whole range of important ways in which support people help, including:

- just being there!
- listening and talking
- finding out information
- taking an interest and taking part in managing MS (for example, going to doctors' appointments, MS Society meetings)
- making adaptations to lifestyle, activities, roles, expectations
- providing different types of support – sometimes emotional rather than practical

How to best support somebody with MS

Most people don't want to see their partner or friend upset and struggling and want to help and support them in some way. However, it is difficult to know what to do in a situation where you can't get rid of the main problem. We found that often there is a mismatch between the amount and type of support that is given and what the person with MS wants and needs. Mike and Sandra are a typical example:

Mike (husband) reported how, when Sandra was diagnosed with MS, he didn't know what to do to help the situation. He was shocked and upset and also wanted to ease her distress. He thought that maybe in the future her mobility would get worse and she might need to use a wheelchair. So he focused all his energy into making changes to the house and garden and building wheelchair ramps.

Sandra (wife with MS) talked about how, when she was first diagnosed, what she really wanted was for Mike to give her a hug! At that time she wasn't ready to make plans for how she would cope with potential disability in the future. She just wanted emotional support and someone to talk to.

There is often a difference between men and women in this regard. Men want to do something – provide advice or do something practical, while women would prefer to talk about how they are feeling. For some people, just listening doesn't feel like doing very much at all, but in fact it is often the most useful thing you can do.

Sometimes we avoid talking because listening to someone in distress can be very uncomfortable and make us feel even more helpless. But research shows that expressing emotions has a number of benefits for health. At first, people are more distressed when they talk about negative things, but over time the benefits show.

Everyone is an individual and wants different support from their family and friends (and different types of support at different times). Here are some questions which it might be worth thinking about, or perhaps talking to your partner or friend about:

- How much does your partner/ friend/ relative want to talk?
- Do they want to express emotions?
- How much help does your loved one want with physical tasks?
- What sort of practical help do they want?
- What sorts of support are most useful for you to give?

Good communication and flexibility are essential here.

We found that a lot of the people with MS found it hard to tell people exactly what they want and need. They also said they found it hard to accept help. Sometimes they felt guilty having somebody help them out. Often they value their independence and don't want to let this go. Your partner or friend will look at these sorts of issues in their sessions with the nurse.

Getting the balance right with helping is important. Although you might feel that it is your responsibility and you should drop everything to help the person with MS, this is not necessarily the case. It is sometimes best not to over-protect or 'mollycoddle' them. Being able to do things for themselves is often important for making people with MS feel stronger, more in control, and more satisfied with their life. You also need to have some time and energy left for yourself.

Dealing with difficult emotions

At times, living with someone with MS is bound to provoke difficult emotions. As Dave explains, it is hard to know where to channel these negative emotions:

“I think the hardest thing is to try and understand why you do feel angry and try to channel it into something, because there is nowhere you can really direct it otherwise. You do feel kind of angry at something which is invisible. It's quite hard.”

Many people told us about how they felt anger and frustration with MS itself, doctors, health care systems, God, and sometimes towards the person with MS. Many people also told us about the sadness and grief they felt to see their loved one suffering and missing out on things they want to do. Anxiety about what may happen in the future is also common, as is worry about the person's health and wellbeing on a day-to-day basis.

All of these negative feelings are completely natural, but unpleasant to experience. Sharing these feelings can be painful, but sometimes expressing them can help to relieve them. Often people think that other people won't understand what they are feeling because they are not in the same situation. But sometimes, just talking and having somebody to listen might help.

- Have you got somebody you can talk to. If so, who?
- Would writing down how you feel help? Some people find talking very hard, in which case writing may work better.
- Would joining a support group or an online chatroom or forum be useful for you?
- Other ways of expressing your emotions can also be useful. Some of the people we talked to found it useful to sometimes have time away from their loved one to do their own thing. Many people also said that physical exercise (for example, going for a run, or a long walk) helped them to reduce their negative emotions.

The important thing is that you find a way to deal with your emotions that suits you. Everyone is different, so you may like to try different ways to see what works best for you. A combination of the things listed is often the most helpful.

Keeping a social life

Many people told us that since their partner was diagnosed with MS their circle of friends had reduced and their social life had become more restricted. There are a lot of different reasons why this might happen. Your partner might be worried about embarrassing symptoms, or concerned about what people will think of them if they are using a stick or a wheelchair. They might not have disclosed their MS to people or may not have admitted to family or friends exactly how difficult things are. If relevant, they may tackle some of these issues in their therapy sessions with the nurse.

Sometimes people feel that others don't understand very well or are unsupportive so they prefer to avoid people. Graham told us:

“I used to quite enjoy going down the pub with my mates, and I suppose because I've found the last few occasions so difficult, I've found that now I avoid it. So yes, I probably am avoiding more than I used to, because I avoid situations which will make me feel worse. Yeah, so it tends to make me more and more stuck in the house...”

Sometimes, people just gradually get out of the habit of doing social things because of the effort involved and the fact that going out can't now be as spontaneous and easy as it used to be. As Lewis told us:

“You know sometimes all the preparation is just too much to bother with and so we end up staying at home, because it's just too much trouble to plan it all, to do it all in advance.”

There might be a need to be flexible about what your social life involves and adapt what you do to make things appropriate for your changing lifestyles. It might be helpful to think of ways you can see people and do things that won't be too much effort and won't cause excessive fatigue and stress. Liz and Matt have found a way to still have fun with their friends:

“Friends come to us now rather than us having to go out into town and find somewhere with easy access and toilets that are not up several flights of stairs! I decided a while ago that I'm not going to get concerned about whether the house is dusty and the oven is not clean to my previous high standards. I get a nice ready meal from Marks & Spencer, shove it in the oven and then we can enjoy the time with our friends without it being a big stress.”

Generally, we encourage people to try and continue to maintain some social activities. Unless you continue to have a social life together, then either one or both of you are likely to become lonely and frustrated. Also, if you start to become isolated and lose contact with people, you might find that your support network starts shrinking. Having a range of people who are available to support you, listen to you, distract you from your problems, and offer practical help will make things easier – now and in the future.

Dealing with other people

Dealing with other people's reactions to MS can be challenging. Often people don't really understand what MS is all about. In particular, they don't understand how bad the fatigue can be, and how a person with MS can look quite well but still be feeling terrible. Some people might care and want to help but just be unable to find the right words. People can become embarrassed or uncomfortable when talking about illness.

It might be helpful to lower your expectations of how other people 'should' respond to your partner's MS. Be open and clear about what is helpful from your friends and family – and what is unhelpful, frustrating and annoying. This might reduce friction in relationships and help you both feel more supported by those around you.

Having your own life

Sometimes MS takes over and becomes the main thing in people's lives. Some people find it difficult to go out and enjoy themselves if their partner can't come along. Katie told us about the feelings this provokes:

"If I went out for a girls' night, I'd feel guilty, I'd feel guilty that I could go out – and on my own. I'd be thinking that Brian couldn't come, so I'd feel guilty about it and I probably wouldn't do it."

Katie also told us that she felt lonely and frustrated because she didn't get to see her friends. That made her feel even more guilty. However, many people with MS told us they felt happier if they knew that their partners weren't missing out completely on what they enjoy. People are less likely to feel a burden if they don't stop you from doing things. Nadia told us about her supportive husband:

"My husband plays in a band, he's got a job and his own interests and I think that's quite good that he keeps sort of going with that, but he's totally loyal and brilliant about everything, so..."

Other partners may find it harder if you go out without them, but there is a balance between looking after your own health and supporting your partner. Ultimately, maintaining your own wellbeing is very important both for yourself and the person with MS. You will have more to offer them support-wise if you feel fulfilled within yourself. Constantly giving out and not getting much back can make people resentful of their role.

So try to make sure that you make time for things that you enjoy, including physical exercise, rest and relaxation and leisure activities.

Looking to the future

In the sessions with the therapist, your loved one will also practise finding ways to react differently to MS. By changing priorities and expectations, people with MS can find new ways of achieving a good quality of life. A key point is that if people with MS have to give up or limit certain things (such as work or hobbies) it is important that they take on new things that they are able to do and that give them pleasure, a sense of achievement, interest and fulfilment.

Charlotte and John told us how they no longer go on long-haul exotic holidays. Instead, they go on more local or European holidays. John misses doing trekking on holidays, but he has recently done an evening course in photography (an interest that he has rekindled from when he was younger) and now enjoys taking photos on holiday.

Many activities (both necessary and fun ones) can be achieved more easily if the person with MS paces themselves (not taking on too much or too little). They will be learning about how best to manage activities and rest during their sessions with the nurse. They will also look at ways to manage symptoms and fatigue and minimise how much they interfere with their lives.

Planning for the more long-term future can be a tricky area, as Keith describes:

“I don’t know what’s gonna happen in the future, that’s the thing that’s really nasty, unknown. That’s what I find scary. It’s just not knowing. Is she gonna be fine for two years? Or she’s not fine, she can’t walk tomorrow? And I don’t know. So how the hell can I plan for that?”

A sense of optimism can be helpful. It is easy to fall into the trap of expecting the worst. In many cases, people with MS do not develop serious disabilities, and have a normal life span with a

good quality of life. However, some people's illness progression is faster and it may be helpful for you to discuss what would happen if and when the illness progresses, and have some back-up plans in place.

Accepting that MS is not going to go away and will be part of your lives is also important – although it can be a very hard thing to do. Acceptance does not mean giving in. Rather, it means not constantly fighting, denying and wishing things were different. It is to do with making the most of what you have got.

Constant adaptations are likely to be necessary when living with MS. Learning to be flexible and getting used to living with uncertainty are beneficial ways of coping. Debbie explains:

“So we've got to deal with it as it comes along. We're finding it easier to deal with because time has helped – from the first understanding of the disease and the longer you live with it... you sort of accept it... you adapt.”

And finally...

We hope some of the information in here has been of some help or provided some food for thought. We realise there will be ups and downs, and for the most part family members cope and adjust very well when someone close to them has MS. The key message is to remember to look after yourself – be kind to yourself rather than always feeling you should be doing more. MS has a profound effect on you as well as the person who has MS, so you are entitled to ask for help and support when you feel you need it.

We also encourage you to attend one of the saMS CBT sessions with your partner, friend or family member. Your partner or friend will discuss this with you and let know when the session is scheduled.

MS Society

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults and we estimate that around 100,000 people in the UK have MS.

MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. We provide a freephone MS Helpline, grants for home adaptations, respite care and mobility aids, education and training, support for specialist MS nurses and a wide range of information. Local branches cater for people of all ages and interests and are run by people with direct experience of MS.

The MS Society also funds around 80 vital MS research projects in the UK.

Membership is open to people with MS, their families, carers, friends and supporters.

You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer.

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

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