

# Making a Difference

## Tips for Living with MS

*Written by & for  
people  
with  
Multiple  
Sclerosis*



**MS Research Trust**



*action for now*

# INTRODUCTION



Graham Smith

This booklet is just one part of a very exciting project, which has involved thousands of people who, like us, have MS.

Back in September 1999, we launched a campaign on behalf of the MS Research Trust, in response to the government's announcement that the National Institute for Clinical Excellence (NICE), would look at the treatments *beta interferon* and *glatiramer acetate*. It was to be decided whether or not these treatments would be provided on the NHS for people with MS.



Cathy Dowsett

Following a number of newspaper articles, radio interviews and a newspaper advert to publicise the campaign, several thousand people requested a questionnaire. In it, we asked people to tell us what they really think about these treatments, and many other aspects of living with MS, so that we could pass on their views directly to NICE. We also invited them to offer tips for others with MS, and this is where this booklet fits in.

In total, 2,599 questionnaires were completed and returned, making it then the largest ever survey of people with MS. The responses were analysed, put into a report, and sent to NICE at the beginning of February 2000.

We would like to say a huge thank you to everyone who took the time to complete a questionnaire and we hope that you find this booklet useful. It is not an exhaustive list of tips and advice, but it has been written by and for people with MS. Many of the tips may not apply to you, but we hope that there is something useful for everybody.

Graham

Cathy

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## FRIENDS & FAMILY



Your friends and family can be an excellent source of help and support. Don't forget that they'll be worried about the MS as well as you. Here are some ideas about how to deal with the people around you:-



### *Tips & Advice...*

- Involve your family from the start
- Don't assume that friends and family will automatically understand your condition: talk to them
- Be open and honest with those close to you, they are probably just as worried as you are
- If you are prone to mood swings, make friends and family aware that what may be fine one day can be a total disaster the next
- Let people help you when help is needed, it's not giving in to MS it's just accepting it
- If you have mobility problems, tell friends and family to let the telephone ring a little bit longer, so that you have more time to get to it before they hang up. Also, invest in an answer machine
- MS doesn't mean you have less to give to family and friends. You may have more

# COPING STRATEGIES



Coping strategies are to do with your emotional wellbeing, and how to keep on top of MS mentally. An overwhelming number of you said that thinking positively was the most important advice they could give, but here are some other things to consider:-



## ***Tips & Advice...***

- Keep a really good comedy on a video tape for times when you feel a bit down - laughter is a great tonic
- When first diagnosed, don't look at other people with MS and assume that it will affect you in the same way. MS is very different in different people
- Try to keep your sense of humour and a positive mind as much as you can
- Look after yourself. Do the things that are important to you and don't feel that there's anything that you 'should' do
- A diagnosis of MS affects everyone differently. You might want to know everything NOW or you might want to know nothing for a while but just have a contact number for when you are ready for information
- Look at what you can do, not what you can't
- Don't think of yourself as ill. People with MS can still be fit and healthy

## EXERCISE



Exercise is really important for people with MS. It can help to keep you strong, supple and mobile. Many of those who filled in our questionnaire said 'use it or lose it'! Here are some of the other pieces of advice that were suggested:-

### *Tips & Advice...*

- Try to exercise little and often, to keep your muscles and joints functioning well and to avoid stiffness, but don't over-tire yourself - be aware of your physical limitations
- Choose a type of exercise that suits you and fits in with your daily routine
- Toning beds are a good way of keeping fit, without being too energetic - you should find them at your local gym or leisure centre
- Swimming is a good all-over exercise, for keeping your muscles as strong as possible, and the water will support your body weight
- If you are at a keep fit class, such as aerobics, only do as much as you can, and sit out of any exercises that you don't feel comfortable with
- Try not to sit still for long periods of time. If possible, stand up and have a walk around every so often, to prevent stiffness in your legs
- If some parts of your body are not as active as others, for example, if you have trouble with your legs, try to do some upper body exercises whilst sitting in a chair
- Exercising with a friend can help to make it fun and keep you motivated

# REST



It is really important for people with MS to ensure that they get plenty of rest to conserve energy. Don't fight tiredness, but listen to your body when it feels fatigued:-



## ***Tips & Advice...***

- Try to ensure that you get enough sleep - take naps during the day if necessary. Give yourself permission to rest and put your feet up whenever possible
- When you feel tired or worn out, stop what you are doing and have a rest before you start again - pace yourself
- Don't stand when you can sit down, and don't sit down when you can lie down
- Be aware of your physical limitations and listen to your body when it tells you to stop
- You might find that relaxation tapes and gentle music help you to wind down
- If you know that you have a big event coming up that might tire you out, make sure that you prepare for it, by getting as much rest as possible beforehand

## MEDICAL MATTERS



Making the most of what is often the short time that you spend with your GP, neurologist, nurse or other healthcare professional is really important for both your physical and emotional wellbeing. These tips are all about dealing with the medical profession effectively:-

### **Tips & Advice...**

- Don't assume that every ache and pain you have is because of your MS. Make sure you consult your doctor if you are worried about something - even if they do tell you that it is because of your MS. Also, make sure you visit your optician regularly - don't assume that problems with your eyesight are necessarily due to MS
- However, don't be fobbed off if your doctor tells you that an ailment is to do with your MS, when you really think that it isn't
- When you see your doctor, make sure that you take a list of questions with you
- Try to visit your neurologist regularly for check-ups - they are the specialists, rather than your GP
- It might help to take a friend or family member with you when you visit your neurologist, as two sets of ears are better than one. They might also remember to ask a question that you had forgotten, or be able to take notes for you



## **MEDICAL MATTERS** *continued ...*

- Try to give your doctor or nurse as much information as you can about you and your symptoms - it will help them to understand your MS, and to treat you as effectively as possible
- Try keeping a diary of your symptoms and taking it with you to consultations. Sometimes it's difficult to remember exact dates when you are on the spot
- Remember that many of the symptoms of MS can be treated, for example bladder problems. Make sure that you tell your doctor everything, even if it does feel embarrassing
- If you don't understand something that your doctor or nurse tells you, don't be afraid to ask them to explain it again, until you really understand it
- Ask your doctor for the contact details of support groups, and other healthcare professionals who can help you, such as physiotherapists and counsellors. Also, find out if there's an MS specialist nurse working in your area
- Always remember that you can ask for a second opinion if you are unhappy with any advice given by a consultant. Your GP can arrange this for you
- When you visit a doctor or nurse, don't feel pressured by time. Take your time and make sure that you get the most out of your appointment
- Try to form a good relationship with your GP, neurologist, the nursing and reception staff - it will help you to relax and feel comfortable with them

# TREATMENTS



Many of the symptoms of MS can be treated really effectively. Here is some advice about treatments that people found useful:-

## *Tips & Advice...*

- Different treatments work well for different people. It might take some time to find out what works best for you, but keep trying until you do find out
- If your doctor has prescribed medicines for you, make sure that you take them as directed, as they may not work as effectively if taken at the wrong dose, or at the wrong times
- Ask if there are any side effects of the medicines that he or she prescribes for you
- Ask your doctor if you are eligible for beta interferon
- Don't immediately reject any treatments your doctor suggests, that you are worried about taking, such as anti-depressants (which are used for a variety of symptoms). Talk through your fears and concerns, and take some time to consider it carefully
- If you have problems with bladder control - speak to your doctor about it, even if it does feel embarrassing. There are treatments that might be able to help you. Also, find out if there is a continence nurse in your area
- Ask for an appointment with a physiotherapist, who will be able to suggest exercises for loosening tight muscles and gentle stretching

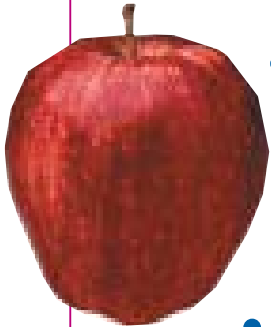
## DIET & DIETARY SUPPLEMENTS



It is generally thought that the healthier you are, the better your body will be at coping with MS. Many people really believe that changing their diet has brought about improvements to their symptoms:-

### *Tips & Advice...*

- Try to watch your weight. Avoid saturated fats and animal fats where possible and watch out for when they are hidden in processed foods
- Eat healthily, with plenty of fresh fruit and vegetables. Eat lots of natural foods and avoid animal fat
- Drink plenty of water and avoid alcohol and cigarettes
- Some have found that drinking tonic water or taking magnesium supplements relieves their spasms
- Eat regularly and don't let yourself get hungry
- Ginger and mint are thought to be helpful for nausea
- If you suffer with bladder problems drink cranberry juice instead of your usual drinks and avoid caffeine
- Ask your neurologist if he or she has an MS diet sheet, and if you can be referred to a dietician
- A very few people are allergic to some foods. If you keep a note of what you eat and drink and how your health is, it can help to identify whether there is anything that doesn't agree with you



## **LEISURE & TRAVEL** *(if mobility is a problem)*



Don't feel that because you have MS, you can't get out and about. Here are some suggestions for how to make the most of leisure and travel:-



### **Tips & Advice...**

- Don't be ashamed to accept all the help that is available. If an orange badge or a wheelchair is a means to an end - use it!
- Many people with MS find that heat does not help their symptoms. During summer months, try to plan activities so that you won't be outside at the hottest time of day - over lunchtime. Putting your feet in a bowl of cold water, cold water sprays and table-top fans will help to cool you down
- Make the most of the activities and hobbies that you enjoy. Make MS fit into your lifestyle, rather than fitting your lifestyle around MS
- When you are going somewhere that you haven't been before, find out where the toilets are, if there are lifts and how wide the doors are

## **LEISURE & TRAVEL** *continued ...*

- If you are travelling by aeroplane, get in touch with the airline directly before you leave, as they will be able to offer you assistance in getting around, both before and after the flight. They may also be able to put you in a seat with extra leg room if you need it
- If you are going somewhere special such as to a restaurant or a concert, it is always worth 'phoning in advance, as they may be able to offer you priority parking or special seating arrangements
- If appropriate for you, investigate applying for a disabled bus pass. If there is an 'access' bus in your area, you and a friend can travel free
- If you use sticks or a wheelchair, take advantage of queue jumping at theme parks!
- If you drive, your car can be adapted with flip up accelerator and hand controls
- When clothes shopping, to tell whether or not something will fit without trying it on, either take an item of clothing with you or your measurements to compare

## LEGAL & FINANCIAL



Don't forget that there are special legal and financial provisions designed to help you. Benefits and eligibility are ever changing. This page includes some tips to help you to find out exactly what your legal and financial entitlements are:-

### *Tips & Advice...*

- Visit the Citizens Advice Bureau to find out about all of the benefits that you are entitled to
- Citizen's Advice Bureau advisors can help with filling in forms, making claims and appeals. They can also make home visits if mobility is a problem
- Make sure that you get everything that you are entitled to - the endless form-filling is worth it
- Check the validity of your current insurance policies and pensions
- Get lots of different quotes when you are looking for insurance policies, where you have had to state that you have MS



## DAILY ACTIVITIES



Sometimes, it's the little things to help with everyday activities that can make a real difference to living with MS. Here are some ways of making things easier on a daily basis:-



### **Tips & Advice...**

- As cool water is generally better for your symptoms than hot, start with tepid water in your bath or shower and increase the coolness as you get used to the temperature
- If you have loss of feeling in your hands, invest in a water thermometer, so that when you get into the bath, you can safely do so without scalding yourself
- If you are registered disabled get a radar key, which can be used for disabled toilets anywhere in the UK
- If someone in a shop, restaurant or on public transport goes out of their way to be helpful, thank them and write a letter to their manager and encourage them to keep up the good work
- If you tend to sit for long periods of time, buy clothes one size larger than you would usually wear, as they will be more comfortable

## AROUND THE HOUSE



Everyday household activities are often taken for granted. We received lots of really simple but useful techniques that can make many household tasks much easier:-



### *Tips & Advice...*

- Mail order clothes shopping means that you can take time to try things on at your own pace
- To help with opening jars, bottle tops and turning door handles, either wear rubber gloves, or affix thick rubber bands for grip. Rubber bands can also help you to hold on to pens and pencils
- Ask to see your local social services officer, as they may be able to help with things around your house, such as handles for getting in and out of the bath, or railings for garden paths
- Keep floors as clear as possible, and arrange your home for your convenience - place furniture in strategic places as supports, to help you get around
- Set yourself realistic goals, for example, instead of trying to Hoover the entire house in one go, do one room at a time and if you still have the energy, do another one

## AROUND THE HOUSE *continued ...*

- Get as many labour-saving devices as you can, and wherever possible, make things easier for yourself. For example, you could move the ironing board down to its lowest level, and do the ironing whilst sitting down, cook whilst sitting down, get hold of tilting stands for kettles and teapots and invest in a cordless phone
- Steamers might be easier to manage than heavy saucepans of water
- If you have to go upstairs to the bathroom, make sure you save up any other things that also need doing upstairs, so that you can avoid making separate journeys. Also, buy duplicate cleaning materials for upstairs and downstairs
- A long-handled shoe horn is excellent for putting shoes on without having to bend down
- If you find that your arms ache when reading for a long time, try lying flat on your back on a bed or sofa, and resting a recipe stand on your chest to support your book. Also, try using an eraser or rubber finger to help turn pages
- Sleeping on an air or water bed might help to ease aches and pains
- Don't feel guilty if you can't take as active a part in daily chores as you used to, let someone else do the washing up for a change

- When you are in the shower, try wearing swimming goggles to protect your eyes when washing your hair. Also, a shower seat will make things easier if standing for long periods of time is a problem
- Make things easy for yourself. Plug lots of electrical devices into one central bank, so that there's only one switch to turn on and off. Also make sure that things you use often are to hand on work surfaces, rather than away in cupboards
- Keep frequently-used objects such as pens in your pocket or in a bum bag, so that they are always accessible
- Use a carving tray or just a chopping board with spikes, to hold food still whilst chopping

## **ALTERNATIVE THERAPIES**



There are a number of different alternative therapies that have been suggested by others with MS because they have found them useful. Some of these include:-



- Hyperbaric oxygen
- Massage
- Acupuncture
- Homeopathy
- Reflexology
- Magnet therapy
- Aromatherapy
- Faith healing
- Meditation
- Yoga
- Tai Chi
- Herbal remedies

# ABOUT THE MS RESEARCH TRUST

The **MS Research Trust** is a charity which has been working since 1993 to provide help and information to people with MS and their friends and families, from the time of diagnosis. It has **three** main objectives:

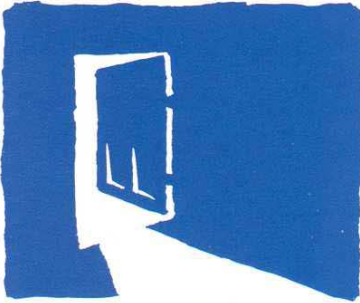
- 1. To provide positive and realistic information to people with MS, their family and friends, and health professionals*
- 2. To fund research which will help people with MS manage their disease, developing therapies and strategies needed to help people cope with MS today*
- 3. To promote MS Nurses - encouraging the development of MS nursing through education, information and communication*

**MS Research Trust**



*action for now*

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If you want to get in touch with the MS Research Trust for further information about what we do, or details of other publications that we have available, please either telephone: **01462 476700**, or write to:

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If you have access  
to the internet,  
you can also visit  
our website at:

**[www.msresearchtrust.org.uk](http://www.msresearchtrust.org.uk)**

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