

Talking about MS

Fact Sheet

Multiple
Sclerosis
Trust

MS

Information

Education

Research

Support

We hope you find the information in this factsheet 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 factsheet 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.

MS Trust information service

Helping you find the information you need

The MS Trust offers a wide range of publications, including a newsletter *Open Door*, which provides an ongoing update on research and developments in MS management. In addition it contains articles from people with MS and health professionals.

For a full list of MS Trust publications, to sign up for Open Door and much more visit our website at www.mstrust.org.uk

Freephone 0800 032 3839 (Lines are open Monday – Friday 9am-5pm)

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Talking about your MS

to family, friends and colleagues

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Contents

| | |
|---|----------|
| 1. Introduction | 2 |
| 2. Telling friends and family for the first time | 3 |
| 3. Questions to consider before telling people about your MS | 4 |
| 4. Getting the support you need from family and friends | 5 |
| 5. People you need to tell that you have MS | 6 |
| 6. Telling your employers and colleagues | 7 |
| 7. Resources from the MS Trust | 8 |
| 8. Contacts | 9 |

1. Introduction

There is no denying that living with MS can be difficult, frustrating and even frightening, particularly when you are first diagnosed. It can take some time to come to terms with the fact that your life is likely to change and it is natural to grieve for what you think you may lose.

In the initial stages, it is likely that only those who are very close to you will be aware that you have MS. Once you have had time to adjust, you may want to think about telling a wider circle of people. Choosing whether you want to do this and how you might do so can be a complex decision. This factsheet aims to provide some ideas to help you to think about these issues.

2. Telling friends and family for the first time

MS doesn't only affect you - it will also have an impact on those around you. Broaching the subject for the first time with family and friends can be daunting. However, keeping things hidden can be a great strain, particularly if symptoms are affecting how you live your life. It can be a relief to get things out in the open.

- There is no right or wrong way to tell people about your MS, just as there is no ideal time. Some people begin by telling only family and very close friends and then gradually let others know when symptoms become apparent or they feel ready to be more open about their condition. There is no need to hide the fact that you have MS and you may prefer to talk openly about it from the outset - just do whatever feels right for you
- You can never predict how people will react when you tell them. They will probably experience a mixture of emotions, just as you did when you were first diagnosed, and will need some time to adjust to the situation
- You will probably know much more about MS than the people you tell, especially about how it affects you. Be prepared for them to ask what might seem basic questions and to work through misconceptions they may have about the condition
- Be prepared for the emotions you may go through yourself when telling people about your diagnosis. It is probably going to be a process you go through several times as you tell different people
- Encourage family and friends to build up a good understanding of what MS is and the issues that are of concern to you. Finding out more about the condition may allay their own fears and helps avoid misconceptions about MS. The MS Trust can provide information on MS in general and on specific symptoms and their management. The book *MS Explained* may be a helpful introduction

Talking to children about MS

- It is particularly difficult deciding when to tell your children that you have MS. How much information you provide and when you do so will depend upon their age and how they might react. In many cases, it can be helpful to start by providing small amounts of information and gradually building up. The book *Talking with your kids about MS* is a guide for parents on how to raise the subject, some of the things children may want to know and what other parents' experiences have been
- If children are quite young, it may be best to answer questions simply as they arise. Children are often concerned that their parent with MS will die. Reassurance that this isn't the case can relieve a great deal of anxiety. The MS Trust book *The kids' guide to MS* is written for children under 10. This gives information about the condition and provides children with an opportunity to talk about MS and to raise their concerns
- For older children and teenagers, you will also need to gauge the appropriate level of information. The MS Trust book *The young person's guide to MS* is written for 10-15 year olds and deals with some of the facts about MS as well as the emotions someone of that age may be feeling

3. Questions to consider before telling people about your MS

- Why do I want to tell them?
- What benefit will there be from telling them?
- What disadvantages might there be?
- Why do I feel they need to know?
- Is this the best time for me to tell them?
- What are they likely to do with the information?
- If I only want a few people to know, will they respect this?
- Am I able to deal with their reactions and questions?

4. Getting the support you need from family and friends

Even if your MS is common knowledge, you may still need on-going support and help from those around you. Most people have no idea what it is like to have MS and you will need to express your needs clearly so that people know how and when to help and support you.

- Be honest and open about how you feel. It is natural not to want to worry your family and friends, but it is important that you feel able to express your feelings when you need to. Putting on a brave face all the time may leave you feeling isolated and frustrated and you risk shutting them out
- Some of the symptoms of MS, such as fatigue, are not obvious to others. Sometimes you will need to spell it out if you need a hand. If your MS makes you prone to mood swings, it might be helpful to warn people in advance so that they know what to expect and don't take it personally.
- People usually want to help but they need to be told how and when. If people seem overpowering, try to take offers of help in good grace but explain how they can be most useful or why you'd prefer to manage on your own for the moment
- If you go through a bad patch and life feels like an enormous struggle, talk to somebody. If you are worried about upsetting those close to you, there are other people you can talk to. For instance, your MS nurse or GP may be able to refer you to a counsellor
- While it is good to talk about your feelings, try not to let MS dominate your conversation at all times. You risk others, and perhaps even yourself, thinking of you purely as a person with MS
- Remember that your family and friends may need your support too and possibly that of health professionals or counsellors. They will probably find it upsetting that you have MS and may have other problems of their own to cope with - it is a two-way process

5. People you need to tell that you have MS

There are some people that you must inform when you are diagnosed with MS.

5.1. Driving

If you have a driving licence, you must tell the DVLA (Drivers & Vehicle Licensing Agency) that you have been diagnosed with MS - (see section 7 for contact details). They will send you a questionnaire to assess the impact of MS on your driving performance and a medical adviser may need to talk to your doctor about your condition.

If the medical adviser decides that there is no medical reason to prevent you driving, a full licence can be retained. If they decide that a further review of your medical fitness is required in the future, you may be issued with a driving licence for a period of one, two or three years.

Should you require the controls of your car to be adapted, the law requires this to be specified on your licence. You must also tell the DVLA if your MS worsens, and this may require a reassessment.

If you are concerned about the effect of MS on your driving, contact the Forum of Mobility Centres. This is a network of independent organisations across the UK that offer information, advice and assessment to people with a medical condition that may affect their ability to drive or use a motor vehicle (see section 8 for contact details).

5.2. Insurers

Insurers require that you declare any relevant information, medical or otherwise. If you don't declare this information, you run the risk of their refusing any claims you might make. If you are in any doubt, check with your insurer about what you are required to disclose.

People with MS are protected from discrimination from the point of diagnosis by the Equality Act. If an insurer refuses to cover you without justification, they may be in breach of this law.

6. Telling your employers and colleagues

If you work, the chances are that you may at some stage want to tell your employer and colleagues that you have MS. This may be because symptoms are affecting your work or because you need adaptations in equipment or working patterns to help you stay in work.

- Deciding on the right time to disclose your MS to the people with whom you work depends on your particular circumstances. Some people prefer to be upfront as soon as they are diagnosed, while others continue working for many years before they feel the need to tell their colleagues, if at all
- There is no legal obligation for you to tell your employer that you have MS unless your condition presents a health and safety risk. However, you must not mislead your employer and you have a duty to answer medical questions honestly
- The rights of people with MS are covered by the Equality Act. This act protects people with MS from any form of discrimination from the point of diagnosis
- A key provision of the Equality Act is that employers are expected to consider making 'reasonable adjustments' for staff who are covered by the Act. What constitutes a 'reasonable adjustment' will depend on your workplace and how MS affects you. Examples include improving accessibility, adapting working hours to accommodate medical appointments or fatigue or supplying specialist equipment. If you work for a large organisation, the occupational health or human resources / personnel departments may be able to help
- When considering whether to inform your employer, remember that if they are not aware of your condition they won't be able to make any 'reasonable adjustments' you may require.
- If you cannot face telling your employer by yourself, ask somebody else to help such as a colleague, your MS nurse or occupational therapist or a Disability Employment Adviser (DEA). DEAs are available through your local Jobcentre Plus

- Make sure that your employer and colleagues understand what MS is, how it is likely to affect your ability to perform your job and the sort of support that would help. Reassure them that you can still make a valuable contribution. The MS Trust can provide information about MS to help you inform your employer and colleagues
- Many employers are extremely supportive and flexible in accommodating changing requirements. You will need to make it clear if your MS is affecting your work. Often it is the 'invisible' symptoms of MS, such as fatigue or lapses of concentration, which can cause particular problems in the workplace but may not be obvious to those with whom you work. If it is an issue, make sure that your colleagues understand that fatigue is a symptom of MS and that you are not being lazy!
- The MS Trust book *At Work With MS* covers a range of employment issues, including telling your colleagues about your condition
- Information about general employment rights can be obtained from a number of sources including the Disability Services Team at your local Job Centre, the Disability Law Service (England only) and your trade union or professional association.

7. Resources from the MS Trust

The MS Trust has a number of other publications that may be helpful when talking to someone about your MS.

- At work with MS
- MS explained
- Talking with your kids about MS

We also have two books for younger people

- The kids' guide to MS (*for 6-10 year olds*)
- The young person's guide to MS (*for young teens*)

All items are free and can be ordered from the MS Trust. They can also be read, ordered or downloaded from www.mstrust.org.uk/pubs

8. Contacts

Driving

Driver and Vehicle Licensing Agency (DVLA)

Drivers Medical Group, DVLA, Swansea, SA99 1DF

0300 790 6806

eftd@dvla.gsi.gov.uk

<http://tinyurl.com/dvla-ms>

Forum of Mobility Centres

0800 559 3636

mobility@rcht.cornwall.nhs.uk

www.mobility-centres.org.uk

Map of Mobility Centres - <http://tinyurl.com/map-mobility>

Employment

Jobcentre Plus

A government agency helping people find work and claim benefits.

Disability Employment Advisers (DEA) help people return to or retain employment

DEAs - <http://tinyurl.com/disability-employment-adviser>

Benefits - <http://tinyurl.com/welfare-benefits>

Working Life Service

A service offered by the charity Neurosupport providing guidance and support about workplace issues to people affected by neurological conditions.

Neurosupport Centre, Norton Street, Liverpool, L3 8LR

0151 298 2999

info@neurosupport.org.uk

www.neurosupport.org.uk/support-services.html

Disability Law Service

An independent charity providing legal information on discrimination and employment rights for people with a disability in England. They have a dedicated MS legal officer.

Ground Floor, 39-45 Cavell Street, London, E1 2BP

0207 791 9800

advice@dls.org.uk

www.dls.org.uk

Equality and Human Rights Commission (EHRC)

An independent body that promotes equality of opportunity and challenges discrimination

England - 0845 604 6610 / englandhelpline@equalityhumanrights.com

Wales - 0845 604 8810 / waleshelpline@equalityhumanrights.com

Scotland - 0845 604 5510 / scotlandhelpline@equalityhumanrights.com

www.equalityhumanrights.com