Making Sense of MS

Multiple Sclerosis Trust MS

Telling people about your MS

A guide to telling people about your diagnosis

When you've been diagnosed with MS, although you're the one experiencing the symptoms, your diagnosis may affect those around you too. As well as being a person with MS, you may be a partner, parent, brother or sister, friend or work colleague. When you're ready, you may want to think about who you'd like to tell about your diagnosis, and when and how much you want to tell them.

This information answers the most commonly asked questions about discussing your MS with other people in your life, such as family members, close friends and work colleagues.

What should I think about?

Should I keep quiet?

It may be tempting to keep things to yourself but being open about your diagnosis, and how you're feeling, can be really helpful for you and those around you.

Who you choose to tell, and when, is really up to you. You might want to keep it private for a while, or you may be happy to tell people straightaway. You might prefer to tell those closest to you first. Or you may want some time to learn more about MS before you try to explain it to others. We have information you can share with people to help them understand your MS (see further information at the end of this sheet).

If you'd prefer not to talk about your diagnosis right now and instead want to take some time to digest everything yourself, that's fine too. You may want to let those closest to you know that you're not ready to talk about it just yet.

Why should I tell people?

Perhaps you're usually very open about what's going on in your life with family and friends. Will they be worrying about what's wrong if you've suddenly gone very quiet or are avoiding doing certain things, for example if you get more tired than before?

People may try to guess what's happened. They may guess correctly or they may be wide of the mark. Sometimes it can be better if people know what's really going on. Giving people another explanation may seem easier to begin with, but it can become difficult to keep this up, or to remember who you've told what.

I had to get my head around my diagnosis before I felt able to tell others.

You may feel more supported if others know what you're going through. This could be emotional or practical support. It could just be knowing people are there for you if you need them.

You might feel that some people need to know. Is your manager at work wondering why you've had time off? Are your wider family wondering why you haven't got as much energy to play with the kids?

Talking to people can be a relief. Discussing your situation and any concerns can bring them into the open and put them into perspective.

Taking the lead

Telling people is something where you can feel in control. Sometimes, you might like others to lend a hand. For example, would it be easier for you if your partner told their own family? This is something that you could discuss and plan with your partner.

However, you may like to set some ground rules for each person, such as whether or not you'd like to be the one to break the news to your wider circle or whether it's OK for them to pass the news on.

What should I say?

It's natural to feel nervous about telling people. You may be worried that people will treat you differently. Remember that you're still the same person – don't be afraid to remind people of that too. What you actually say is a very personal decision and you can tailor it to fit the person you're telling, depending on how much you want them to know.

You may want to say something about MS generally but also describe what MS is like for you, for example by talking about some of your symptoms. You may prefer to keep it brief to begin with. You can fill in more detail as you learn more yourself or become more comfortable talking about your MS.

Your MS nurse may be able to help by explaining the condition to close family, or by giving you some pointers on starting the conversation yourself.

You might like to have some printed information about MS which you can give to people. It's probably best not to overwhelm others with too much information. You can always refer them to our website when they're ready to know more.

It's about listening too

Telling people is only part of the task; it can be good to listen and reflect too. What might happen when you tell them? They may be surprised, shocked, uncomfortable, fearful, tearful or angry. They might need time to learn about MS and come to terms with it too. They will probably have their own questions about what it means for all of you.

Don't be surprised if their reaction to your diagnosis, or their way of dealing with it, is completely different from your own or from how you thought they might react. Often people don't know what to say so they might not say anything at all, or even say something that seems inappropriate. Remember that they do care about you so try not to take anything you find upsetting too much to heart.

I've been touched by the consideration shown to me by my friends. Some don't know how to react, but almost all of them have been brilliant throughout. It's not a burden you need to carry by yourself.

Being prepared for different reactions

There's no correct way for others to react to the news of your diagnosis so you may well experience a wide range of responses.

Some people may want to learn more about MS and be keen to discuss sensitive topics that you might not be ready to talk about just yet. Others may respond in a more introverted way and may not want to go into the details – this may be because they're feeling uncomfortable rather than because they don't care.

You may find that some people instinctively want to protect you. This might be what you'd like, but equally it may be very unwelcome and feel overbearing. If it becomes too much, it's best to be clear with that person exactly what sort of support you'd prefer from them.

Keeping the conversation going

You don't have to cover everything in that first conversation. You could spread it out over time.

In the long run, it's good to keep the channels of communication open as far as possible. Even if you, or your loved ones, aren't ready to have an in-depth conversation now, it's important that everyone feels they can ask questions when the time feels right.

Telling family and friends

Many people begin by telling their closest family and friends. You might like to begin with the person you feel closest to or you could choose whoever you think will be the most understanding.

Some people may seem overly concerned or protective. They'll most likely have your best interests at heart, but if their reaction is overwhelming you then do make them aware of this.

Your family will naturally want to look after you but this should be done in a way that's acceptable to you. It's good to have support but also to feel in control of your life with MS.

It can be particularly difficult if you're a young person with MS, perhaps living with your parents. Your family can be as involved as you'd like them to be, for example you may, or may not, want them to come with you to your appointments. If you're over 18, you're legally entitled to make your own decisions. Your family, however well-meaning, can't make decisions for you and they have no automatic right to attend appointments with you or see your medical records.

Telling children

If you have children, the prospect of telling them may seem really daunting but they're often more accepting than you might think. Very young children may not understand even the simplest explanation so you might choose to wait until they're a little bit older. Older children will probably be glad of an explanation as, just like adults, they may be wondering what's going on. They may even be imagining a much worse scenario, so you might not want to wait too long before putting their concerns to rest.

My kids were very resilient and were happy to ask questions and read literature for young teenagers.

Every family is different and you'll know how, and when, your family usually shares important news. You might like to choose a time when everyone's relaxed, but not distracted by things like the TV, so you know they'll be listening. You might like to tell everyone together as children are rarely good at keeping secrets from each other, even for a short time. Sometimes the right opportunity to tell your children may just present itself, despite any plans you may have had about when and where you were going to tell them.

You can choose words which are easy for them to understand and you don't have to go into a huge amount of detail initially. You might like to begin by talking about the symptoms your children might have noticed already. For example, they may know that you've been getting really tired or can't walk very far at the moment. Now you can explain why.

It's good to let your children ask questions. It's fine to say "I don't know" or "the doctors don't know" if you're not sure of the answer. Try to be as honest as you can and keep the conversation open so your children know they can ask you more questions in the future. As they grow up, their own understanding of MS will change, and they may want more detail so it's important to keep the lines of communication open.

Telling your employer

In some jobs, for example if you're in the armed forces, you must tell your employer straightaway. However, in most jobs, you don't have to disclose your diagnosis and, if MS isn't having an impact on your work, you may choose to wait. However, your colleagues may wonder what's happening or they could potentially misunderstand your symptoms.

You may prefer to tell only your manager and close colleagues, especially if you'll need time off for appointments. If your symptoms are causing you any difficulties and you would benefit from changes to your working pattern or environment, then you'll need to disclose your diagnosis so your employer can support you appropriately. Once you've disclosed your MS, your employer is required by law to make reasonable adjustments to support you at work.

Sharing information through social media

Some people find it helpful to share their news and experiences through social media and learn from others with MS. You may feel that sharing your diagnosis through your usual social media channels is a good way to let your wider circle know what's happening. Equally you may not feel comfortable sharing personal information in this way – do whatever feels right for you.

Before sharing any personal information on your social media channels, you may want to review your privacy settings to check how widely your posts and other activity can be seen. You may want to adjust your settings to find a balance that you feel comfortable with.

You might like to follow some MS charities on social media to get the latest news and research. You can join online groups like the MS Trust Facebook group to ask questions and share experiences. Again you might want to think about whether groups are public or private before you post.

All my friends and family were very supportive when I told them. They don't fully understand the nature of the condition but they are all very understanding and don't treat me any differently.

New people in your life

Inevitably, there will always be new people coming into your life. These might be new work colleagues, friends or a new partner. Once again, you'll need to think about whether to tell them about your MS, and when and how you want to tell them.

Over time, these conversations are likely to get easier as you get used to talking about your MS.

Got a question about MS?

Ask our Helpline Team on 0800 032 3839
or email ask@mstrust.org.uk

Scan to support the MS Trust

454-Telling people about your MS.07.24.2K

Further information

Making Sense of MS information sheets:

Someone I know has MS mstrust.org.uk/441

MS and your feelings mstrust.org.uk/447

Making Sense of MS: newly diagnosed with MS mstrust.org.uk/448

Other publications from the MS Trust:

Talking with your kids about MS mstrust.org.uk/316

Information on our website:

MSTV, our YouTube channel for young people affected by MS mstrust.org.uk/MSTV

Support groups mstrust.org.uk/support

Disease modifying drugs mstrust.org.uk/dmd

MS Decisions mstrust.org.uk/decisions

Research and MS mstrust.org.uk/about-ms/ms-research

Working and studying with MS mstrust.org.uk/life-ms/wellbeing/managing-work-and-study

Printed publications can be ordered for free or downloaded from our website. Alternatively, they can be ordered by calling 01462 476700.

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Making Sense of MS

This information is part of a set of resources for people who are newly diagnosed with MS. You might like to look at our introductory resource, Making Sense of MS, which answers the questions most commonly asked around the time of diagnosis.

MS Trust Information Team
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