

There are many sources of information and advice about telling those closest to you about your MS. Your MS nurse or doctor will be able to help. You can also try the organisations below:

[www.msactivesource.co.uk](http://www.msactivesource.co.uk)

[www.msactivesource.ie](http://www.msactivesource.ie)

[www.msdecisions.org.uk](http://www.msdecisions.org.uk)

The following organisations are also available to help:

Multiple Sclerosis Society  
[www.mssociety.org.uk](http://www.mssociety.org.uk)  
Helpline: 0808 800 8000  
email: [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

Multiple Sclerosis Trust  
[www.mstrust.org.uk](http://www.mstrust.org.uk)  
Tel: 01462 476700  
email: [info@mstrust.org.uk](mailto:info@mstrust.org.uk)

Irish Multiple Sclerosis Society  
[www.ms-society.ie](http://www.ms-society.ie)  
Helpline: 1850 233233  
email: [mshelpline@ms-society.ie](mailto:mshelpline@ms-society.ie)



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Thinking about telling family and friends



Supporting you  
each step of the way

# Questions about telling friends and family

## How do I tell people I have MS?

With MS it can be a struggle to explain your diagnosis to friends and family, especially if you are getting over the shock of having the disease yourself. They might need reassurance, and they may not know much about MS. If this is the case, you will need to explain what it is and how it will affect you. They will want to help, so explaining how your disease may progress will mean you can work together to cope with MS day-to-day.

It may be that when you are tired and need help with housework or shopping, friends or family can take over. Or partners may be able to step in to help care for children, prepare meals or just understand when sometimes you feel down.

It might be worth thinking about how and where you want your family and those closest to you to hear the news. You may want to tell everyone at once or to stagger the process. If you feel your parents can relay it to other members of the family, this may be less draining for you. On the other hand, you may only want a few people to know at first. It's important not to rush into telling people if you don't feel ready. And you will need to prepare yourself for mixed reactions.

It's also worth remembering that your dentist will need to know, as you may have reduced sensation or be more prone to infection. And because MS can affect all parts of your body, it's worth considering whether you'd want to tell your hairdresser or anyone else who works on your body too.

## When do I tell people I have MS?

This is up to you and is a very personal decision. You can maintain a relatively normal day-to-day life with MS. Many sufferers, with the right treatment, go on

for a long time without anyone knowing they have the disease. It is important, though, that if you need support you don't suffer in silence. Those closest to you would not want this to happen.

## What do I say to my work colleagues?

Make sure you have adjusted to the news yourself before considering telling people at work. Before making a decision about telling your boss or colleagues, it's important to look at your work place and the type of work you do. For example, if you are a teacher or driver, MS will affect your daily work much more than if you are in a 9-5 desk job.

Another thing to bear in mind is the severity of your symptoms and whether you really need to disclose your medical status. There is no legal requirement to do so.

Generally employers will be very supportive. But if you do experience problems, you can talk to your MS nurse who will be able to recommend sources of advice. Telling work means you will be less worried about taking time off sick or for hospital appointments. Employers may also be able to negotiate a schedule that relieves you at times when you need treatment.

## Why did I get MS?

There is no particular reason why people get MS and the cause is still unknown. It is possible that a virus or environmental factor triggers a process where the body's immune system turns against itself and damages the myelin covering the nerves. A person may be more prone to MS because of characteristics passed down from generation to generation in their family.

## What if they ask me what it is?

If you find you need to explain the disease you can mention that MS affects the central nervous system. So this has an impact on all parts of what would otherwise be a healthy functioning body. It might be useful to talk about the effect on you day-to-day, for example, how you might forget things, feel dizzy or numb, can hear one minute and not so well the next, or feel up and down.

## What if they ask me about the future?

Explain that MS is an unpredictable condition – one in which some people may experience relapses and notice that the disease progresses relatively quickly whilst others may find that they can go for many years without any change in their condition. There's no way of knowing how MS will affect you individually. However, with treatment and a good support network of family and friends, you can work through challenges together as they arise.

## What can they do to help?

There are a whole range of things that friends and family can do to support you. Helping you exercise is one thing. Or making sure you have a regular, healthy and balanced diet. They could help you stay positive by encouraging you to keep up your hobbies and interests. They can take over so you can have rest periods or naps to restore yourself. They may also notice symptoms that you don't.

Everyone's experience of MS will be different. But talking through things with the people who may be impacted by your illness will help them understand more of what is involved. The more they know, the better equipped you will all be to work together to make your life easier.