

Talking with your kids

about MS



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1. Talking with your kids about MS

There is no denying that living with MS can be difficult and at times frightening, particularly when you are first diagnosed.

MS affects not only you but those around you as well. As a parent, you may consider talking with your children about MS. Choosing whether to do this can be a complex decision.

Each family is unique and each person's experience of MS is different. As a parent, you know your own circumstances and your own children best. That makes you the best judge of how to discuss MS with your family, when the right time might be and what you might tell them. There is no right or wrong way to do it, just as there is no ideal time.



This booklet aims to provide some ideas to help you think about these issues and answer some of the concerns that you may have. It doesn't tell you exactly what to say to your children but it will give some suggestions about how to tell them, some of the things they may want to know and what other parents' experiences have been.

It will help you talk about your diagnosis with your children and continue to have open and honest discussions in the future.

Although we mostly refer to the parent with MS throughout the text, in many families partners may want to be included in discussions and you may need to agree a common approach.

What if we don't talk?

Most people affected by MS will at times experience some of the darker emotions such as anger, fear, sadness and confusion. Many people need time to consider what MS means for them before they feel ready to talk about it to their children.

It is natural to want to protect your children. If your symptoms are mild you may prefer not to tell them, at least for the time being. There are no set rules and a lot will depend on the age of your children and how you usually talk to them about health and other problems in the family.

“I spent a lot of time thinking I should tell my daughter but on the other hand wanting to avoid burdening her unnecessarily.”

But it is difficult to hide things from children. They notice subtle changes in mood and hushed conversations as clues that something is not right. If they feel left out, they may make up their own story, which may well be far worse than the truth. They may sense that the cause for concern is secret and so don't share their distress. For some children, this can be expressed in their behaviour, schoolwork or friendships.

There is also a possibility that if you don't tell them, they might find out some other way and think they are to blame.

What if we do talk?

We know from research and the experience of other families that children do need to know if their mum or dad has MS.

“When I found out that my dad had been diagnosed with MS 2 years ago and I had not been told I was furious. While I could see the reasons why, I felt hurt. I felt like I had lost 2 years with my dad, as I didn’t spend the time with him that I could have.”

The good news is that when you include your children in discussions, when they are encouraged to talk about their own feelings and are made to feel that their opinions matter, you may be helping them adjust to the highs and lows of life in general. They need to be able to trust you, and being honest with them helps them to do that.

Keeping things hidden can be a great strain. It is often a relief to get things out in the open.

“I was dreading telling my children about my diagnosis, and I was going to put it off for as long as I could. But in the end they found out in a very unplanned way. They were very upset, but then had a lot more understanding about what had been happening to me. I thought I had been protecting them, but in hindsight they’d been confused and worried. They were all so young but I hadn’t credited their intelligence.”

Children can be very supportive and may surprise you by doing or saying something which shows how they understand.

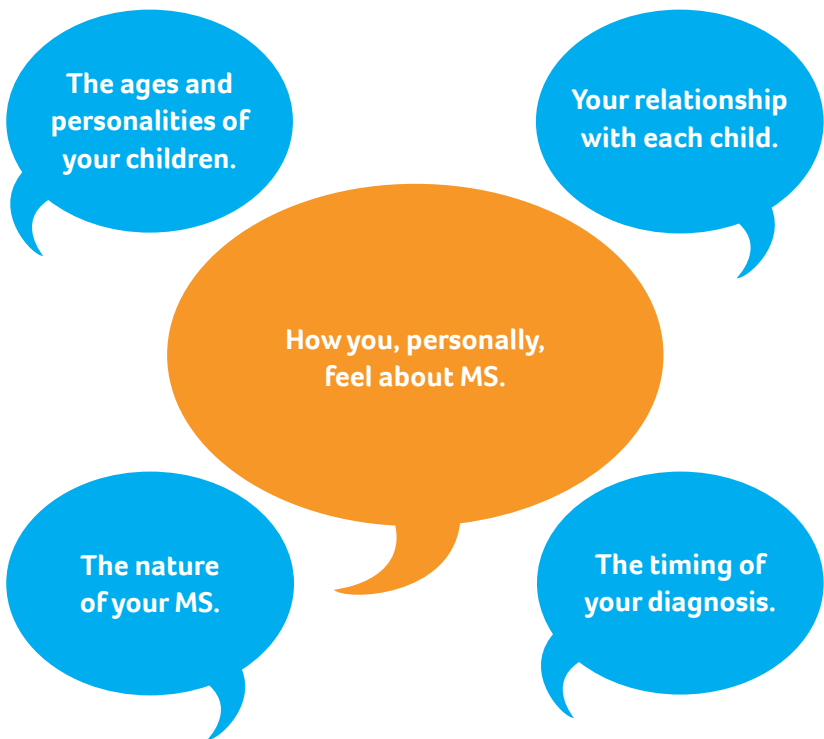
Not all children will be understanding; some may appear unconcerned about MS and, like some adults, try to ignore it. Others may have a more negative reaction – they may express indifference, hostility or become withdrawn.

Talking about MS for the first time

If you have decided to talk to your children about MS, the next big challenge is finding the right moment for a first discussion. Broaching the subject for the first time can be daunting; you might find it helps to discuss what you plan to say with your partner or a friend before talking with your children.

It is important to take the lead in talking about MS. Some children will not ask questions, even if they are worried, for fear of upsetting you or because they feel the topic is 'off limits'.

There are several things that might affect when you feel the time is right to have a first talk.



Many parents prefer not to have a 'formal' family meeting.

"I definitely did not want to sit them down and talk specifically about the MS – it just seemed too contrived and not natural."

"I told them while we were doing some simple craft activity together. My youngest gave me a cuddle and we all carried on with our cutting out. I found this easier for all of us than a more formal 'Please sit down, I've got something to say'."

"I was diagnosed whilst in hospital so I took my daughter, aged 9 to the hospital café and after reading up on exactly what happens in the body during attacks, I drew her simple diagrams to show her what happens and how it affects me."

The first talk you have with your children about MS is important. It opens up the topic for discussion and sets the tone for further conversations about MS in the family. Children soon realise if you would rather not talk to them and will think they can't talk to you. If you are falsely positive they might think they can't admit to their own negative feelings. It is better to admit that you don't have all the answers; if you tell them things that are not true they may find out and feel unable to believe your reassurances in the future.



Keep the first talk simple.

You don't need to cover everything about MS in one conversation.

Reassure them that you love and care for them.

If you have more than one child it may be best to begin by telling them all together so that they start with the same information, at the same time. You can talk to them individually at a later date, as and when they need to.

“Tom and Sarah were 16 and 14 when I was diagnosed. We have always been honest and open with them; this is obviously difficult because we don’t know all the answers, but we have tried to find answers together.”

“Keeping it open and not hidden away should also make it easier for them to ask questions when they are ready.”

It is often useful to ask them what they know about MS so you can correct any misunderstandings.

Older children need to know that you have MS so they can understand when they hear others talking. You could explain that ‘multiple sclerosis’ or ‘MS’ is just a name for the problems you have had. You can describe how your MS might affect family life, like in the examples below.

- Sometimes MS makes me forget things so we must all make sure we write things down on the calendar, or;
- Sometimes I get very tired and have to rest and recharge my batteries, but I am OK.

For younger children, you might feel that ‘multiple sclerosis’ is too much for them to understand and may prefer to talk about physical problems as they crop up.

“When my daughter was 4, I discussed things as they occurred – relapses, fatigue, medication etc but didn’t use ‘MS’. I always explained that whatever was affected wasn’t working properly and this worked well until she was about 8 when she started asking more direct questions. This suited me too, as I was more accepting of my diagnosis and experienced with living with MS.”

Some children seem to accept a short chat and are quick to return to the next activity. If that is the case don't push them to talk as they may need to think things through over a longer period of time.

“My boy doesn't ask questions, and doesn't seem to want to talk about it, but not in a negative way. Having grown up with mummy's poor legs, perhaps he accepts it as normal for his mummy.”

The important message is that all their feelings and questions are OK and that MS can be talked about as much or as little as they need.

Keep talking

Talking about MS is not an isolated event. Listen for any openings your children give you when they ask a question and be prepared to tease out any worries that might lie behind comments they make.

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. Parents know when their children are most likely to talk and the best conversations may happen at meal times, in the car or even at bath time!



**Create opportunities
for your children
to ask questions.**



**Talk about how
you are from
time to time.**

“I have always discussed MS with them all through their lives using terms they would understand.”

Some children may feel more comfortable turning to the parent who isn't diagnosed with MS for support, to a grandparent or a close friend. They may also talk to brothers or sisters when they don't want to talk to parents.

“They talk to each other and discuss it amongst themselves quite a lot more than I realised at first.”

Sometimes children may ask questions that shock or upset you. Whilst it is important to be open and honest with your children, it is essential that they don't stop asking questions for fear of upsetting you. If one of their questions or comments takes you by surprise it might be helpful to say something like *‘That's a good question – I need a bit of time to think about that one, can we talk about it later?’* This will give you time to deal with your immediate emotional response and think about how to respond.

It's important that you do answer their question later though, so that your children don't stop asking questions in the future. This will let your children know that they can talk freely about MS – even the uncomfortable topics – and all their associated feelings.

Will they be upset?

The evidence shows that children can cope with an enormous amount when adults are open and honest and children are made to feel that their feelings and opinions are important.

Everybody experiences negative feelings in life. All children need to learn to cope with upsetting things. Giving your children the skills to understand and express their negative emotions about MS will give them a good resource for life.



All children need to learn to cope with upsetting things.



Let your children know their feelings are important.

Some children will seem completely unaffected by a parent's diagnosis; others may become more withdrawn or show changes in their behaviour. All these reactions are normal and children need to be reassured that whatever they are feeling is reasonable and the same as other children would feel.

“It is quite alright on bad days to say, today isn't going well.”

You and your family can help them most by expressing your own feelings, happy or sad. A partner might say *'It makes me sad that Mum can't come and see your play today, I wish she didn't have MS'*. A parent with MS might say *'I've been feeling so tired today, I just didn't have the energy to hang the washing out. I was so angry with myself!'* Conversations like this will let them see that other people in the family sometimes feel negative things and it is fine for them to say when they feel angry or upset about MS.

“Don't hide the awkward or unpleasant parts of MS. They need to know MS is no easy thing and sometimes you need help.”

“At times my daughter gets frustrated with me and at the same time angry with herself for feeling that way.”

2. What should I tell my kids about MS?

Conversations about MS with younger children may be much simpler and shorter than conversations with older children and teenagers. Most children study the human body at primary school and may surprise you with their level of understanding.

“When questions were asked I always tried to answer them with basic easy facts and explanations that they could understand at their age. As they have got older the explanations have been more in depth and detailed. The thing that surprised me was how interested they were in MS and were sometimes ready for more detailed information earlier than I thought.”

Your children are unique individuals and they will ask many interesting and challenging questions. If you feel you need to brush up your own knowledge, the MS Trust has a range of publications and a website which can provide answers to these questions. The MS Trust Information Service or your MS nurse can also help you prepare answers.

Research suggests the following questions are most frequently asked by children.



“It is amazing how my children were able to understand the information. I don’t think they are too young to deal with it, they are amazing at their age (11 and 7) and wanted to know and more importantly having the knowledge helped them ask questions.”

How did you get MS (...and will I get it)?

Children are puzzled by why a parent has MS and will wonder if they might get MS too. Younger children may only have experience of infectious illnesses like colds or chickenpox; they may presume MS is caught from others and then worry that they might get it by personal contact. Older children are generally more knowledgeable about genetics and may be concerned that they will inherit MS too.

You can explain that MS is not caught from other people. Occasionally more than one member of the same family does have MS, but this is not very common. These issues need to be discussed in a way that is relevant to them.

“The children have not asked any difficult questions but they are concerned whether MS is hereditary.”

Can you die from MS?

Most children who are old enough to understand that people die, will want to know if you might die from MS. They need reassurance that although sometimes MS can make people very ill, this doesn’t happen very often. Most people with MS will live a long life.

“Find a way to explain to your children that they will understand. Make it simple, draw diagrams, make it fun where you can but above all make it clear that it isn’t a death sentence and that you will be there for them.”

What's going to happen?

Many children ask questions about whether MS will get worse and how that will affect their future. They worry about what will happen to them if you go into hospital or can't look after them. It is important that you acknowledge the uncertainties of MS and also admit that it worries you too. However, you can reassure them and let them know that they will always be involved when practical changes are planned.

“My daughter asked me ‘Will you be able to help with my children?’”

Is it my fault you've got MS?

Younger children in particular relate everything to themselves and may worry that they have somehow caused MS. People may link their MS diagnosis to important family milestones like pregnancy and birth. They might say *‘My MS was fine until James was a toddler,’* or *‘I really went downhill after I had my first child.’* Children may misunderstand such statements to mean they caused the MS.

All children need to be told that the MS is never anybody's fault and that if they are naughty or behave badly it may make you cross (as it would any parent) but it won't make your MS worse. If you think your children are trying too hard, let them know that they can't make it better either and encourage them to follow their own interests.

“When she was 6, a situation arose where it became evident that she thought there was some association between her behaviour and me being ill. It never crossed my mind that she would think this.”

3. Should I get my kids to help?

It is vital for all children's self esteem that they become increasingly independent and contribute to family life. Don't make the mistake of doing everything for your children. Children as young as two can tidy their own toys, older children can keep their rooms tidy, pack their own lunch boxes and do basic household chores.

“Dylan knows that mummy may want a bit more help with things around the house when she is having a bad day, and he is (normally) happy to help in his own little way, even if it's just to get the phone for mummy or something.”

Children like to help and simple, practical tasks are ideal. This is fine as long as they know you are not dependent on their support and do not feel it is their role to be your carer. If children realise you need them for certain aspects of your care they will worry about what will happen if they are not there. This can lead to problems at school and fears about being away from home.

If at all possible children should not be involved in personal care e.g. toileting. It is important to make sure your essential care is provided by adults or professionals. Your social worker, GP or MS nurse can help you arrange this.

**Teach your kids
life skills from
an early age.**

**Let your children
help with simple
household tasks.**

**Make a plan
together for the
unexpected.**

4. What can I do to help my kids?

Teach your children as many life skills as you can from an early age. Encourage them to take responsibility for their rooms and help around the house. This means if you are unwell or having a bad day they will not suddenly be expected to do things they are not used to doing every day.

Encourage them to make friends and spend time with other people so that they feel they have someone to talk to as well as you. From an early age, create opportunities for them to stay away from home overnight or for a few hours at a time. All these skills will mean that if you have a relapse or a stay in hospital your children will feel confident that they can cope.

Make a plan together for the unexpected and maybe give it a special name. You could agree what would happen if, for example, you were unable to collect them from school, who would collect them and where they would stay if you had a medical appointment or needed to spend time in hospital.

Allow them to choose the people they would feel happy to stay with overnight. Create a trial run so that your children know exactly what would happen if an unplanned situation occurred.

You might find it helpful to make sure other key people in your children's life know about your MS, such as a friend, teacher or club leader. You might want to tell other close friends and family your approach with the children as it will be confusing if they are given conflicting information.

“He can talk to me about it if he needs to, there are others he can talk to as well. School and friends know about it.”

5. When should I ask for help?

A few children will cope less well and may need some additional help. Some difficulties may come and go quickly, just as they do in many children who don't have a parent with MS. Some changes in behaviour may reflect other issues like the birth of a new sibling or a problem at school. If you talk to your children about MS as they grow up you will be in a better position to judge whether behaviour represents a serious problem.

Children express their distress differently according to their age. Some children might revert to behaviour that is more appropriate for a younger child like day or night incontinence; they may become very clingy and show signs of significant anxiety.

Some children express their negative feelings by behaving badly, having severe temper tantrums or being unkind to others. Older children may withdraw or become consistently angry. If you have any concerns about your child's psychological or physical wellbeing it is important to raise these concerns with a professional you trust, such as a teacher, your MS nurse or GP.

In extreme cases, children may display signs of mental health problems like obsessional behaviours, severe anxiety, eating disorders, self injury, suicidal thoughts or substance misuse. If you see these behaviours talk to your MS nurse or GP about how to obtain professional help.



**Children express
their distress
differently.**



**Speak to a health
professional if you're
worried about your
child's behaviour.**

6. Finding the positives

Family life can be good despite having MS.

Any life-changing experience can alter your perspective on life. Children can gain from their experiences of having a parent with MS. Many children grow up with a greater sensitivity to the needs of others.

Children often enjoy more quality time with a parent, doing things like talking, reading and playing games, which improves the quality of relationships. Children may need to learn to be more independent than others their age and it is well established that increased skills lead to greater self esteem, coping ability and confidence in children.

“We made a book that includes the adventures of our family and the positive and negative experiences that MS creates.”

One of the positive aspects of MS is that many parents with MS think more about the emotional issues for their children. Children will grow up with a better understanding of health and how to cope with negative emotions. Living with MS is a powerful opportunity to learn about coping with challenging situations in life.

“We laugh a lot and tease each other so much that my children’s friends think it’s strange that a woman in a chair is treated so.”

“At the age of 9 my eldest son presented to his classmates a short talk on ‘My Hero’ – he chose me! And it became a talk about 20 minutes long with some very mature questions from his class.”

7. Further information

MSTV

MSTV is our YouTube channel for young people who have MS themselves or who have a family member with MS. Since launching the channel, we have created a range of videos to help young people better understand MS, the symptoms it can cause and what can be done to manage those symptoms. Featuring young people talking openly and honestly about their feelings and experiences, MSTV reassures young people that they're not alone and supports them in dealing with the emotional impacts and social challenges that MS can bring.



Visit the MSTV YouTube channel and watch our videos at youtube.com/MSTVUK

Online resources

For more information on family life with MS, visit our website mstrust.org.uk/life-ms/relationships-and-family-life

For further resources for young people affected by MS, visit mstrust.org.uk/life-ms/young-people-and-ms

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There is a solid pink vertical margin strip along the left edge. The paper appears to be part of a notebook or binder.

About the authors

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Jo Johnson has specialised in neurology since 1995. She has worked extensively with families and facilitates groups for the partners and children of people with MS and brain injury. She has written books for both children and adults who are affected by long-term neurological conditions.

Information Team, MS Trust

We are a UK charity that believes nobody should have to manage multiple sclerosis alone. We are here for everyone affected by MS, from the moment of diagnosis and throughout their journey.

Thank you

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