

Talking with your kids about MS

Multiple
Sclerosis
Trust

MS



Jo Johnson
Janice Sykes

Jo Johnson

Consultant Neuropsychologist

Jo Johnson has specialised in neurology since 1995. She has worked extensively with families over the last ten years and facilitates groups for the partners and children of people with MS and brain injury in Sussex.

Janice Sykes

Information Officer, MS Trust

The MS Trust is a charity working with and for people in the UK with multiple sclerosis (MS). Our vision is to enable people with MS to live their lives to the full.

We provide:

- information that is tailored to what people want to know
- education for health professionals about what people with MS need
- research into better management of MS
- support for anyone affected by MS

Thank you to

- All the parents with MS who have made this book possible through sharing their experiences
- For their help in preparing this publication:
Dr Alexander Burnfield
Kerry Mutch
Vicki Matthews


Jo Johnson, Janice Sykes MS Trust
Talking with your kids about MS
ISBN 1-904156-19-3
© 2010 Multiple Sclerosis Trust
Registered charity no 1088353

All rights reserved. No part of this book may be reproduced, stored in a retrieval system or transmitted in any form by any means, electronic, electrostatic, magnetic tape, mechanical, photocopying, recording or otherwise without written permission of publisher.



Contents

Talking with your kids about MS	4-15
• What if we don't talk?	
• What if we do talk?	
• Talking about MS for the first time	
• Keep talking	
• Will they be upset?	
What should I tell my kids about MS?	16-19
• How did you get MS (...and will I get it)?	
• Can you die from MS?	
• What's going to happen?	
• Is it my fault you've got MS?	
Should I get my kids to help?	20
What can I do to help my kids?	21-22
When should I ask for help?	23
Finding the positives	24-25
Further information	26-27



Shall I tell the kids?

When shall I tell them?

What do I tell them?

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 yourself 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.



Tracy

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.



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.

”

Lucy, 16

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, they will grow up to be as happy and well-adjusted as other children.

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 a strain. It is often a relief to get things out in the open.

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.

“ 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. ”

Nicola

“ My children were all adults by the time my MS began to be noticeable, they all jumped to the conclusion that I had a brain tumour and so MS was quite a relief. ”

Ann

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.

”

Andrew

“

I told them while we were doing some simple craft activity together. I thought it would be easier for me and them to do it in a matter of fact way. 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.

”

Jane

“

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.

”

Kathryn

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 it simple.

*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. ”

Alan

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

Lee, husband of Faye

That first conversation needn't cover everything about MS. Keep it simple. The most important message is to reassure them that, whilst things might change, you love and care for them now and always.

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 link any problems you might have with the MS and tell them how these might affect the family:

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 starting asking more direct questions. This suited me too, as I was more accepting of my diagnosis and experienced with living with MS. ”

Tracy

“ We don't describe Faye's condition to the children as "multiple sclerosis" as they wouldn't understand. Multiple sclerosis is a very big word for a young child, we just call it MS. ”

Lee, husband of Faye

“ I immediately discussed my diagnosis with my elder two girls and with my youngest child when she was five. ”

Wendy

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. ”

Lisa

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, so talk about how you are from time to time, tell them how you got on at an exercise session or a hospital visit, create opportunities for questions. 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!



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

Lesley



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. Once I was aware of this I knew I could rely on the eldest to share the information with his siblings if they wanted more information and felt awkward about asking me.

”

Andrew

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 as well as let your children know that they can ask about uncomfortable topics. It's important that your children know they can talk freely about MS 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.

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. ”

Andrew

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. ”

Lesley

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

Tracy

*Shall I tell
the kids?*

*What shall
I tell them?*

*They may surprise
you with their level
of understanding*

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. ”

Andrew

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 (for a list of publications, see the Further Information section). The MS Trust Information Service (contact details at end of book) or your MS nurse can also help you prepare answers.

“

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.

”

Julie

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



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 rare. 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.

Wendy

’

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.

Kathryn

’

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?"

”

Julie

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 down hill 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 six, a situation arose where it became evident that there was some association between her behaviour and me being ill. It never crossed my mind that she would think this.

”

Tracy



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. ’

Lee, husband of Faye

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.

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.



I got in touch with a young carers group, he went out with them at times, with other young carers for social outings and they were helpful, also meeting other young carers.



Carole

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. ”

Carole



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.

*We still
have fun.*

*My eldest taught
me to play tennis
on the Wii...*

*...and now I
give him a run
for his money.*

Finding the positives

Family life can be good despite having MS.

“

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.

”

Sarah

“

His friends come round quite a lot, and he often tells me that they think I am the nicest mum they know. I think it is because I am pretty laid back because of the fatigue.

”

Carole

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.



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



John

Children often enjoy more quality time with a parent, doing things like talking, reading, playing games on a playstation or Wii, 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.

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.



I feel proud of the way that I have brought him up concerning the MS, even though I'd rather not have it at all. He doesn't see it as a big issue much of the time which is fantastic.



Carole



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.



Andrew

MS Trust Information Service
T: 01462 476700
E: info@mstrust.org.uk
www.mstrust.org.uk

Further information from the MS Trust:

MS: what does it mean for me?

For people newly diagnosed with MS – a practical introduction to MS to help answer questions at a time of uncertainty and maintain a positive attitude.



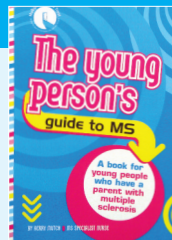
MS Explained

A guide to what MS is and to help people understand the mechanisms of the disease.



The young person's guide to MS

Written with the help of 10-16 year olds who know what it is like to have a parent with MS and who share their experiences, worries and emotions about living with MS in their family.



Kids' guide to MS

Aimed at 6-10 year olds who have a mum or dad with MS. Fully illustrated in bright colours with engaging characters, this is a book that children can read on their own or with a parent.



Other organisations:

Parentline Plus

A charity which offers support to anyone parenting a child.

T: 0808 800 2222

E: parentsupport@parentlineplus.org.uk

www.parentlineplus.org.uk

MS Society of Canada

The Growing Up Strong project was undertaken by the MS Society of Canada in 2002-2004 to support children of parents with MS. A report of the findings is available on the website.

www.mssociety.ca

MS Society

Provide a variety of publications and web-based resources to help explain MS to children.

T: 0808 800 8000

www.mssociety.org.uk

YCNet

The Princess Royal Trust for Carers - Young Carers site
An interactive website with information, discussion boards and live webchats for young people.

T: 0844 800 4361

www.youngcarers.net



Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T 01462 476700
E info@mstrust.org.uk
www.mstrust.org.uk

Registered charity no. 1088353