

Life with MS:

Mastering Disclosure



MASTERING



Multiple Sclerosis

Essential Information About MS

Multiple sclerosis (MS) is a disease that attacks the central nervous system (CNS). MS usually progresses over time, but early diagnosis and treatment may help slow disease progression. It is important that people recognize the symptoms of MS as early as possible. Research has found that starting treatment after the first clinical attack suggestive of MS could slow disease progression and delay disabilities. People with MS who begin treatment after their diagnosis can also benefit from long-term, consistent treatment.

For more information about MS, visit:

<http://www.ms-gateway.com>

Mastering MS

Mastering MS is a global awareness campaign designed to illustrate how MS can affect a person's personal relationships and work life, whether as a spouse, parent, child, friend or coworker. The campaign shows that with the right tools, people with MS can continue to lead physically and emotionally fulfilling lives. The campaign offers resources to help people with MS manage their condition, as well as to better cope with changes that may occur in their personal and professional relationships.

Dear Friends,

Deciding to tell family and friends that you have MS is a highly personal decision. When the time comes to tell people, there is no right answer regarding who you should tell, or even how and when you broach the subject.

Disclosure can be fraught with many fears – *Will people think differently of me? Will they no longer see me as capable or competent? Will I no longer be invited to the pub or parties with friends?*

Open, honest communication is the foundation for strong, loving relationships. Talking to the people closest to you – a spouse, parents, siblings and children – about MS is important. These are the people who will provide the most support.

Before having this conversation, first make sure that you are able to handle your diagnosis both emotionally and psychologically. And prepare yourself to answer questions calmly and confidently to ease the worries and fears of others. Some people will not react the way that you may expect, so prepare yourself for all different reactions. But above all, expect the unexpected – you may be pleasantly surprised by the people you love.

This brochure provides tips to help you make your disclosure a positive, supportive experience. It is difficult to predict how people will respond to your diagnosis, so use the resources that are available in your community. Always remember, you are not alone.

Denise Knauer

Honesty is Important

Even if your friends or extended family don't know about your condition, you can still protect your relationships while respecting your wish for privacy.

For example, if you aren't feeling well, don't push yourself to go out for a late evening at the pub or to a dinner party with friends. Chances are, you won't have a good time and the people around you will notice. They may even feel resentful or hurt. It also may not get you an invitation when you're ready to go out.

Be honest – whether you want a quiet night at home or are ready to go out dancing, your friends will respect your feelings. Honesty can help prevent misunderstandings or hurt feelings in the long run.

“I want people to see me as Betina, not as a disease. A lot of people have diseases, but they manage to do things anyway. Yes, maybe people do need to make some allowances, but I'll let them know myself if that's the case.”
– **Betina, Scandinavia**

Telling Your Partner

Many people facing an MS diagnosis often worry about appearing less attractive or becoming a burden to their partner. Fears of inadequacy or abandonment are not uncommon in people who have just been diagnosed with MS.



But your partner can be your greatest source of support and comfort during this difficult time.

“Nothing in my relationship has changed. My husband has helped me at all times to be strong and to go on living life as a normal, healthy person.” – **Isabel, Spain**

Your spouse or partner should be the first person you talk to about your diagnosis. Talking openly about your feelings with your partner can ease unfounded anxieties. A loving partner needs to understand what you are feeling physically as well as emotionally so that he or she can provide you with the right support. This includes providing moral support when it comes time to tell other people in your life, particularly your children.

Making a Difficult Conversation Easier

Telling a partner or someone very close to you about an MS diagnosis is stressful. Will they be angry or afraid? Will the diagnosis negatively affect your relationship?

These four steps can help alleviate your stress and make the conversation with your loved one easier.

1. **Find a quiet time to talk:** Set aside time when you and your partner will both be away from distractions, such as work or children. Find a private place where you feel comfortable talking openly and honestly.
2. **Teach your partner about MS:** Alleviate unnecessary fears by sharing information about the condition. Researching information together – in a book or on the Internet – can spark a discussion. It's also a great way to bond.
3. **Take your partner to the doctor:** Having a medical expert present when you tell your partner about your diagnosis can help ease tension. A calm, knowledgeable doctor can relieve anxieties and offer guidance, as well as give your partner an opportunity to ask specific questions.
4. **Talk to a relationship counselor:** Outside support from a trained professional can help you bring up difficult topics with your spouse. A relationship expert can ensure each person feels supported while adjusting to life with MS.

Telling Your Children

Children are very perceptive – they may sense something is wrong even before you've had a chance to tell them. Deciding on the best way to tell your children, and how much information to give them, is something only you can do. Depending on how old your children are, there may be ways to explain MS that will be easier for them to understand.

Be aware that children of all ages may react to the news by misbehaving or acting out. They need to understand that everything is okay. Do your best to show them they have nothing to worry about.

Young Children

Mikael of Denmark has been symptom-free since his children were born, so his children have never “seen” the disease. Therefore, he decided to talk to them about his MS when he felt they were old enough to handle the topic.

“I told my daughter about MS when she was six years old. She learned about it when we went on a ‘family weekend’ with other families with MS. She finds it a bit exciting and is very interested in what it's about. We've also read several children's books about having parents with MS.”



Mikael made the right decision to wait to talk to his children until he felt they were ready. Telling children about your MS is a very personal decision. Every family is different, so deciding when to tell your children will be vary from family to family. When you feel your children are old enough, be sure to answer their questions in clear, simple and age appropriate language.

Also, when telling children, it is good to have another adult with you, like a family member or close friend. This gives children another avenue to get answers to their questions, and comfort.

Deciding not to tell your children when symptoms are clearly present or you are taking your medication regularly is not healthy for the family.

Keeping your MS a secret is not very useful either. Children are intuitive so it is best that they know the truth, before they begin to imagine all sorts of 'untruths'.

Older Children

"My son, Yvan, went on the Internet and did a search for 'sclerosis.' By mistake, he came across a life-threatening form. He then shut himself off and became very quiet. When we finally asked him what was wrong, he said, 'I didn't know MS could kill. Nobody told me!' We had another look together at the pages and discovered the mistake. I became aware of how important it is to talk to each other, and also to say what is bothering you."

– Gerard, France

Having the right information can ease anxiety. When you talk to your children about MS, have materials available that they can read, such as books or pamphlets. There are also many great resources for MS online; however, be sure you are getting information from a credible source such as the <<INSERT COUNTRY'S MS ORGANIZATION>>.

Older children often take on extra responsibilities when a parent has MS, so make them feel appreciated.

Let your children know that you are willing to have an honest discussion about their concerns. They also should play a role in family decisions; otherwise, they may feel hurt or resentful. A family counselor can help all family members voice their feelings and concerns.

Approaching Your Children

Children look to their parents for strength and support. Telling them you have a chronic disease like MS can make them feel insecure. Here are some ways you can approach that conversation to dispel your child's fears.

- **Don't go it alone:** Involve another adult family member in the conversation. Whether it is your spouse, parent, or even a sibling, it is comforting for a child to see that everyone is there for support.
- **Be ready for questions:** Children ask a lot of questions – what is MS? How did you get it? Will I get it? What will happen to you? Do your research first so you can address their questions calmly and confidently. Read a book or pamphlet with your child, or research information online together. The children's book "BENJAMIN – My Mum is Special" is a suitable book to read with children ages five to ten. It explains some of the most common symptoms of MS and answers many questions. It's a good resource to help your child better understand what you are experiencing.

- **Use simple language:** Avoid any confusion by explaining things in terms children can understand. For example, tell them that taking medicine is something you will need to do to take care of yourself, just like brushing your teeth. This will leave little room for misunderstandings.
- **Let them know you are the same person:** Children need to be reassured that their parent or loved one will still be there for them. But it is important to explain any changes or accommodations that the family will need to make to their normal routine. Make sure they understand that these changes are manageable.



Telling Your Parents

It is difficult for any parent to learn that their child has a chronic illness such as MS. Mothers and fathers may blame themselves.

Monique of The Netherlands knew it would be hard for her parents to learn about her MS, especially since her mother, grandmother and uncle also had MS. *“I have never been afraid they wouldn’t support me, I just saw how sad my mother was because my brother wasn’t feeling well at the time and I didn’t want to ‘drop another bomb.’ But eventually, after I finished all of the physical examinations and tests, I asked my mother to join me for the last exam. She was there to support me through this last step and was able to ask the doctor any questions that she had.”*

As with your partner and children, make sure you are prepared to answer questions when you tell your parents. The more information you can give them, the easier it will be to ease their fears and concerns.

Going Beyond Your Immediate Family

The degree to which you are comfortable with your friends, extended family, coworkers and other people in your life will help guide your decision whether or not to tell them about your MS diagnosis. Examine those relationships and consider telling people with whom you have the closest bonds.

“There are many people around me who don’t know I have MS. Sometimes when you explain how you feel or how you are, people start treating you like a different person. I don’t want that.” – Isabel, Spain

Telling friends and extended family can provide you with additional people in your life that you can rely on for support.

“At first, I was worried to tell my friends, but when I look back I realize it doesn’t matter. My condition has definitely changed the way I relate to my friends. I’ve come to realize I won’t be able to participate in every social get-together with my friends, because it’s beyond my strength. I have to save my energy. At first, my friends kept asking, why? But now they understand my situation.” – Lidia, Poland

Expect the Unexpected

Don't make assumptions about how people may or may not react to your diagnosis. Your friends and family may surprise you.

Karl, a native of Austria, was a practicing neurologist in the United States when he was diagnosed with MS. *"Some of my neurologist friends were actually not as supportive and seemed more uncomfortable than I expected them to be after I disclosed my diagnosis."*

Given the reaction of his colleagues, Karl thought the news would devastate his elderly parents and waited a year before telling them.

But when he finally told his parents, *"they said, 'okay, you're a neurologist, so you know what to do and how to treat it.' I have to admit, when my parents were pragmatic and nonchalant about it, it was not the reaction I expected. I was surprised and sort of relieved. They took it better than some of my neurologist friends."*

Contributors



Denise Knowles is a certified relationship counselor, psychosexual therapist and media specialist. She has more than 16 years of experience helping couples and families deal with different life issues, including the challenges associated with the diagnosis of a chronic illness like MS.

Resources

- More stories from friends and families of people with MS can be accessed at www.ms-gateway.com
- The children's book "BENJAMIN – My Mum is Special" can be ordered from Bayer Schering Pharma, Specialised Therapeutics, 13342 Berlin, Germany

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All the people with MS mentioned in the "Mastering MS" brochures have been diagnosed with multiple sclerosis (MS), and are currently receiving treatment for their disease.

The testimonials represent each person's own experience, both with the disease and any treatment history. Statements regarding MS treatment represent the individual's own experience and perspective. Not all people receiving treatment will have the same results.

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