

# Accelerated Cure Project for MS

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## Parenting with MS – Should we tell the kids?

Being a parent is a challenging task. When MS enters the picture, this task can be even more difficult. A parent with MS must tend to their own needs (which may, at times, be more pressing), in addition to those of their family. The physical disability often caused by the disease may pose problems in many aspects of raising children. Parents with MS may find themselves too fatigued to take part in their son or daughter's extracurricular activities. [Cognitive difficulties](#) can result in slower thinking, memory loss and difficulty multitasking (an essential skill for most parents). This can make it hard to plan meals or help with homework, among other things. Emotional difficulties may also be challenging for parents with MS. As we mentioned last month, [depression](#) is common in people living with the disease, which can make childrearing feel overwhelming. For some, the fear that children will develop MS adds to these unnerving feelings. While MS may make parenting harder, it doesn't make it impossible. With teamwork and creativity, it's possible to find solutions to challenges that may arise.



One of the most perplexing decisions mothers or fathers with MS must face is telling their children about their disease, if at all. One difficult aspect of this decision is determining how much information to give them. Some parents talk to their children on a "need-to-know" basis, telling them only about things they can see, such as going to the hospital for treatment, or using a new mobility aid. However, children are smart and perceptive, and can often sense problems, and react to them, before they can be seen. Their imagination may conjure up a reason for why their parent doesn't feel well, which may be far worse than the truth. There is also a possibility if they are not told, they may find out some other way. Either scenario may cause undue stress for all concerned. [Research](#) suggests children have more difficulty adjusting when their knowledge and understanding of MS is limited, particularly young children. According to investigators, those that are unaware of their parent's MS

may experience high levels of anxiety and distress due to witnessing family tension without being aware of its source. Other [studies](#) confirm children with limited knowledge of their mother or father's disease tend to experience more difficulties. These results illustrate the importance of open and honest communication with children about MS and its symptoms. Beginning this dialogue early on allows a child's understanding of it to grow and develop over time. That being said, every family is unique and each person's experience of MS is different. Individuals generally know their own circumstances and children best, and therefore are the best judges of how to proceed in this regard.

Conversations about MS may vary depending on the age of the child. Discussions with younger children may be much simpler and shorter as the big picture may be too much for them to understand all at once. The National



MS Society (the Society) offers a [Keep S'myelin Activity Book](#) for children ages 5–12 that may be a helpful resource for this age group. Older children may need to know more about MS and its treatments so they have a better understanding of any symptoms their parents may be struggling with, or to avoid any misunderstanding from a conversation they may inadvertently overhear. The Society's brochure entitled "[When a Parent Has MS: A](#)

[Teenager's Guide](#)" is intended to provide useful information and insight to teenagers or young adults. It's important to note that each child may have a unique learning style. Some may find written materials helpful, while others may respond better to talking. Some children may feel more comfortable sharing with the parent who isn't diagnosed with MS, or if they don't want to speak with a parent, they may prefer sharing with a grandparent, sibling or close friend. For those who benefit most from videos, [the Society's YouTube Channel](#) offers a number of educational movies for parents and children living with MS. Some kids benefit from accompanying their parent to a doctor's appointment, while others find this too upsetting. No matter what their age and stage, it's important to validate a child's feelings, let them know they can ask questions, and allow them to talk about MS as much or as little as they need to. Youth may ask many interesting and challenging questions. The best strategy is to answer any questions they have as simply and honestly as possible. As children grow up their understanding of MS will change and they may want more detail. It's essential to keep talking in order to provide this important information. This open communication not only reassures children that it's okay to talk about MS, but also helps set the stage for effective communication about other important topics that may arise.

[Studies](#) show when families begin talking about MS (and no longer keep it a "secret"), understanding between parent and child improves and the pressure parents may feel trying not to let MS "show" is alleviated.

Broaching the subject of MS for the first time with children may be daunting and finding the right moment a challenge. Many factors may affect the timing of this first conversation, such as the number of children involved, their ages and personalities, as well as the parent's relationship to them. The nature of a parent's MS, the timing of their diagnosis, as well as how they personally feel about the disease may also be influencing factors. In any case, the initial conversation is important as it opens up the topic for discussion and sets the tone for future



conversations about MS. In cases where individuals with MS have more than one child, some feel it's best to begin by telling them all together so they start with the same information, at the same time (and talk them individually at a later date, as needed). Others prefer not to start with a family meeting. In either case, the first conversation can be simple (it doesn't need to cover everything about MS). The most important message is to reassure children that, while things may change, they are loved and cared for.

Children may react to the news in a variety of ways, both positive and negative. How they respond often depends on the child's age and stage of development. It's also important to note that children may change their reactions as they reach different stages of life. A younger child may relate everything to him or herself and worry that they might have caused their parent's MS. Some may revert to behavior that is more appropriate for a younger child. Others may express their negative feelings by behaving badly. Older children may withdraw or become consistently angry. In extreme cases, children may display signs of mental health problems like obsessional behaviors, severe anxiety, eating disorders or substance misuse. If negative reactions occur, it's important to remember the upheaval children feel may not be entirely due to MS, particularly during the teenage years. There are many other obstacles youth may encounter at this time in their life that can cause emotional difficulties. Parents should not automatically assume a change in their behavior or mood is the result of MS. The National MS Society's [counseling services](#) and [support groups](#) are among the many resources available to help parents tease out the source of their child's difficulties and help with any problems that may be beyond what can be managed at home.



A recent [review](#) of 70 studies showed children who have a parent with a chronic illness like MS struggle more with their body image, tend to display [somatization](#) (turning a mental state, like anxiety or depression, into physical symptoms), and have more difficulty relating to others (tend to withdraw more) than children with healthy parents. This research summary suggests children living with parental MS also experience significantly more emotional problems (such as anxiety, fear, and depression) and behavioral problems (for example, aggression and delinquent behavior). Investigators concluded caregiving duties and the stigma attached to a parent's MS were sources of stress for children, especially for adolescents. This age group was stressed by these added responsibilities and had fewer social relationships. [Researchers](#) in the United Kingdom have confirmed this negative social impact on teenagers. Other [investigators](#) suggest that children of parents with MS feel a greater sense of burden and obligation than children of healthy parents, and also a greater degree of anger. A [2015 study](#) explored the negative impact of parental MS further and concluded the emotions and distress expressed by the parent impacts adolescents' psychological difficulties more than the severity and type of their MS.



There is also evidence that children adapt very well when they learn their mother or father has MS, and an open communication about living with the disease has a number of benefits. This can provide children a living example of how to effectively manage challenging situations in life. [Researchers](#) at Penn State University found adolescent children of parents with acquired physical disabilities like those that may occur in MS report spending more enjoyable free time with

their parent. Results showed family members tend to joke with each other more, which improves relationships between all concerned. The research team also found the vast majority of adolescents didn't mind or even enjoyed the household tasks they frequently helped their parents with. Another [study](#) suggests having a parent with MS leads to children feeling more grown up, empathetic and sensitive to the needs of others. Interestingly, [investigators](#) in Denmark found children of MS parents receive higher grades in school and often choose a health-related education in college.

Ora Grodsky, owner of [Just Works Consulting](#), has facilitated [ACP's Leadership Summit](#) for the past two years. Ora's mother was diagnosed with relapsing remitting MS in 1985, when Ora was 24 years old. Today, Ora's mother is significantly disabled. In Ora's words, "I don't know that I'd heard of MS before my mother was diagnosed and I didn't know much about it... My mother having MS has certainly made me more aware of issues of disability. It's made me a more empathetic person because my expectations of her have to be realistic." As mentioned in our [July 2018 newsletter](#), Richard Cohen is a well-known journalist, television producer and bestselling author. Richard was diagnosed with MS when he was 25 years old. Richard and his wife, Meredith Vieira, openly talked about MS with their three children as they were growing up. In his words, "We were very understated, as reassuring as we could be without being dishonest. Once you create a culture of openness in the house, they're not afraid to ask questions ... it all becomes very casual and second nature." Now that his children are grown, Richard shares that his children watch over him. "They're just very tuned in to it ... on the one hand you don't wish it on your children, and on the other hand I really do believe that kids become better persons for growing up in a family with illness. They learn very early that life is not fair. They understand, on a very basic level, that it can be painful. They're fully aware that they are in a position to help and I think it just becomes second nature to them... So, it's not entirely just the 'down' side you've got to deal with. I think there's an 'up' side, too."

Parenting with MS requires a good game plan. First and foremost, it's important for parents living with the disease to take care of themselves. It's important to try to eat and sleep well, exercise, and adhere to their MS treatment plan to keep their disease under the best control possible. Individuals should strive to plan, pace and prioritize



activities to conserve energy and avoid situations that will be overtiring. This will also serve to keep stress and anxiety to a minimum. It may be helpful to encourage family members to pitch in around the house and do age-appropriate chores. Teach kids as many household tasks and skills as possible, starting at an early age, and encourage them to be independent. Not only parents benefit from the assistance, many children enjoy helping and doing so may boost their self-esteem. It's important for parents to be open and honest with their children about their MS and any symptoms they may be experiencing. These difficult times may serve as "teachable" moments for children to help them learn kindness and compassion for others. If mom or dad isn't feeling well, distraction may come in handy. Pulling out a toy or game to play together may help the whole family feel better by focusing on something else. Above all else, try to maintain a sense of humor. Being a positive role model by embracing difficulties with a laugh or smile will not only help ease them, but sends a positive, powerful message to young members of the family.

In general, children have a much more difficult time understanding and coping with the less visible symptoms of MS such as fatigue, visual difficulties or sensory changes. They may misinterpret these problems (for example, mistaking a parent's fatigue for disinterest). There are a number of creative ways to teach kids about these "hidden" symptoms. For instance, to show them how fatigue feels, ask them to walk for a few minutes with weights on both feet. To demonstrate visual distortion, have them look through a pair of eyeglasses with a smear of petroleum jelly. To give them a sense of the awkwardness that can come with sensory changes or weakness in



the hands, let them try to unwrap a candy or button a shirt while wearing a pair of rubber kitchen gloves. Whether a parent has MS or not, it's essential for them to show interest and participate in their child's activities to the best of their ability. If disability poses a problem, take full advantage of mobility devices to stay involved (even if these aids are not needed at home). Experts suggest that children want their parent to attend their school or sport function, even if they are in a wheelchair or have a cane, as opposed to not

attending at all. [Research](#) shows having a social network makes it easier for a child to cope with having a sick parent. It may be helpful to encourage children to make friends and spend time with other people so that they feel they have someone else to talk to. There is [evidence](#) that support from the healthy parent is of vital importance in this regard, as well. Once MS is a topic that is openly discussed in a household, some may find it helpful to offer their child the opportunity to talk with other children who have a parent with MS. The National MS Society offers family [programs](#) where children can connect with their peers and learn more about MS.

According to George Bernard Shaw, "The single biggest problem in communication is the illusion that it has taken place." Open and honest dialogue about MS between parents and children is very important. Accurate information about the disease can be very reassuring to children and help them feel more secure. It can create a boundary around their fears so that overactive imaginations don't make things more frightening than they need to be. It can provide children with a vocabulary for asking questions and help prevent children from blaming themselves unnecessarily for hardship or changes in the household. Information can reduce the need for secrecy and thereby promote an atmosphere of openness and trust within the family. Communicating openly about the challenges that MS brings to your life, and the coping strategies you are using to meet those challenges, gives children the important message that family members can work together to meet life's challenges, whatever they may turn out to be.

