

When a Parent Has MS

A TEENAGER'S GUIDE

FOR CHILDREN AND TEENAGERS



Beverly (front cover), diagnosed in 2001.

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Thanks and acknowledgments for essential materials, quotations from teen group members, and advice on the issues from Pamela Cavallo, MSW, author of the original edition; Melinda Gaffney; Rosalind Kalb, PhD; Deborah Miller, PhD; Wendy Sullivan, CSW; and contributors to the Teen InsideMS project of 2000. Additional thanks to teen volunteers at the Central New England Chapter and to members of the National Programs Advisory Committee.

This publication is supported by contributions to the National Multiple Sclerosis Society from its members and friends.

Reviewed by members of the Client Education Committee of the National Multiple Sclerosis Society's Clinical Advisory Board.

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Introduction

This booklet explores the experiences of some people whose parents have MS. Some are teenagers and some are young adults who remember what it was like. Their problems range from minor annoyances like having to be extra careful not to leave things on the floor, to deeper emotions of anger, embarrassment and guilt. They agreed to share their stories and suggest some ways of dealing with what happens when a parent (or someone else at home) has MS. Excerpts from essays written by Society scholarship recipients have also been added.

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How your parent's MS affects you

If you've been living with your parent's MS for a while, you already know MS isn't the end of the world. But you're not a bad person if you have some gloomy thoughts. All teens of a parent with MS have to put up with a lot more than their peers with healthy parents face. Here are some common experiences teens have shared with people at the National MS Society:

More Chores

"We have a lot of chores that my friends don't have," said Anne. "We have to make dinner, clean up, do the laundry — all that stuff that my friends' parents usually do."

More chores usually means less time for sports, getting together with friends, or doing the things you like. "Last summer I couldn't go to the beach with my friends because I had to do things at home," said Matthew. "And now that I have my license, I'm always getting asked to drive here, drive there."

Nobody wants extra chores, but some kids note that there is a silver lining. Elizabeth wrote in her scholarship essay, "I might have more responsibility than other kids, but I have learned to be more independent and self-sufficient."

And Emily wrote, "I have gained an understanding of the importance of being reliable and dependable. These characteristics will continue to be valuable throughout my life."

Unpredictability

Because MS symptoms can rise and fall like a seesaw, it's hard to know what to expect from one moment to the next. A person with MS may feel fine for months and then suddenly become weak or tired. "You can't do anything spontaneously," said Caitlin. "And things can go wrong at the last minute. We were going on a vacation last year, but my mother had an exacerbation* just before it, and she couldn't go. The trip was canceled. It was a bummer, but that kind of stuff seems to happen a lot in our family."

A parent's moods and memory can also be unpredictable. He or she may have outbursts of anger, or may give permission to do something one day only to forget it the next. "If I tell my mother something, I never know if she'll remember it," said Josh. "Like I'll want to go to a concert, and she says yes, and then later she blanks out about it."

Getting places is also often complicated and unpredictable. A parent with MS may be OK to drive one day and unable to drive the next. "You spend a lot of time finding people outside your family to drive you places," Adam said.

Dealing with the unknown can be a challenge, but Amy wrote, “Having a parent with MS has given me strength to know that the unexpected happens, and I am better prepared to handle unpredictable situations.”

* Exacerbation: the appearance of new symptoms or the aggravation of old ones, lasting at least 24 hours; synonymous with attack, relapse, flare-up or worsening.

Money Strains

There’s no question that MS can put a financial burden on a family. There may not be enough money for extras like music or sports lessons, new clothes or the movies. As Rachel expressed, “You can’t ask your parents for money, because medical costs use up most of what they have.”

Money for the future may also be a worry: “I’m afraid that we won’t have enough money for me to go to college,” said Todd.

Growing up with the financial impact, a chronic illness can seem unfair, but kids often also learn early the importance of being financially responsible. As Jessica added, “dealing with financial hardships has taught me the importance of working hard and getting a good education.”



Emotional Feelings

The Guilt Trip

Sometimes adults will use a parent’s MS as a way to get a teenager to conform. Some kids have said their teachers use guilt to get them to do better in school.

Even parents can put this burden on their kids. “Both my parents will ‘guilt’ me, saying I’m causing stress,” said Kayla. (There’s no compelling scientific proof that stress makes MS worse, but it can make any of us — with or without MS — feel worse.)

In addition to being made to feel guilty, your own guilt can creep in for any number of reasons. Lashing out at a parent in anger, hurting a parent's feelings out of frustration or embarrassment, slacking off on household chores, or fighting with a sibling can all make a person feel guilty afterward.

These feelings are not unusual, but can be lessons. "I am getting past my attitude of treating all my problems as unwarranted attacks against my happiness," wrote Zach. "Instead I am seeing them through more mature eyes as necessary sacrifices."

Lack of Understanding

Only someone who lives in a household with MS knows what it's really like. And that can make a teen feel isolated. Heidi expressed this feeling: "My friends don't understand the pain I feel seeing my mom in pain and me not able to help. They don't understand why my mom is always napping. They don't understand why one day she's on her feet and happy, and the next day she's in her wheelchair, depressed."

"Friends say they understand but they don't really get it," said Eric. "They don't understand how mad I get when they put people down for being 'different.'"

Getting Angry

It's normal for everyone in a family to feel angry now and then about the demands that MS creates. It's normal to feel anger at the illness itself. But sometimes it's hard to separate the illness from the person who has it.

Toni had this to say about her mom: "She can be really annoying, and I wonder if she could do more things for herself if she only tried a little harder. I think she sometimes uses MS as an excuse. I don't know why this had to happen to her, to our family — to me! I love my mom, but she can make me so mad."

"I despised MS most in the world," wrote Christina. "I blamed MS when my parents got divorced, I cursed it when my family didn't have enough money for me to do things I wanted. I always found a way to use MS as my scapegoat. In time, I found a way that I could benefit from the disease. I transformed my father having MS into personal independence and never letting an obstacle, no matter its size, warrant an end."

Feeling Forgotten

People are naturally concerned about someone with MS and will inquire how that person is doing. But that can make other family members feel left out. "No one asks about you or what you're doing," said Kayla.

Being Afraid

Parents are supposed to be the ones who are strong, who are in charge. Parents are supposed to make their **kids** feel safe. When a parent has MS, fragile health turns that “supposed to” upside down. “I worry a lot about my mother,” said Beth. “She has an electric scooter and I worry that she’ll get robbed out on the street. I love her, and I don’t want anybody taking advantage of her. She’s always in the back of my mind.”

Many people in a family with MS worry about their parents’ future ability to function. “Who will take care of her? How will that affect me?” are questions that invade the thoughts of many a teen whose parent has MS.

“If someone were to ask me if I wanted my life to be different, I would say maybe not as difficult, but I can’t picture it any other way. The situations I have had to face have allowed me to discover the value of human life,” wrote Krista.

Embarrassment

Having a parent who uses a cane or a wheelchair, or who has poor coordination or slurred speech, can make the whole family stand out in a way that feels uncomfortable.

Kevin remembered a painful episode: “When I was about 9, Mom came to my soccer game in her wheelchair. Some kid said, ‘Who’s the kooky lady in the wheelchair?’ and I pretended I didn’t know.”

“Sometimes strangers look disgusted, and I know they think my dad is drunk or retarded,” said Jessica.

Parents sometimes express strife in the home because their kids were embarrassed to bring friends home for dinner, declined to inform them about school picnics, etc., or they refused to sit at the same table as them in a restaurant.

Emotions are messy. They don’t march in neat rows or take turns appearing one at a time. They get all mixed up. It’s normal to love and be angry with a parent at the same moment. It’s possible to worry about the future, be impatient to leave home, and still feel tied to your family by loyalty, love and responsibility.

Stevie wrote, “I admit to being uncomfortable at times, but I have gained a wealth of knowledge from having a parent with a disability. I have a gift that allows me to look past stereotypes and aesthetics, which is vital in getting to truthfully know someone.”

You may recognize yourself in some of the situations we described, or you may not. Everyone is unique, and even within the same family brothers and sisters experience life with MS in different ways. The point to remember is this: You are unique, but you are not alone.

What you may not know about MS

Sometimes just getting the facts about MS can make things easier. For instance, difficulty with walking and poor coordination are two obvious and common symptoms of MS. But many other common symptoms are invisible. They affect the person's behavior and emotional state. Knowing more about them can explain why a person with MS is irritable or hard to live with. Here are some of them:

- Dizziness
- Weakness
- Fatigue
- Tingling
- Numbness
- Loss of balance
- Temporary loss of ability to move legs or arms
- Blurry or jumping vision
- Hot or tight band of pain around the torso
- Crampy or extremely tensed muscles (spasticity)
- Pain in a body part for no apparent reason
- Headache
- Need to urinate without delay

- Constipation
- Emotional roller-coaster feeling
- Poor memory for recent events
- Inability to make decisions quickly

These symptoms are caused by slowed nerve conduction (the nerves' ability to carry messages). They are all recognized MS symptoms. They come and go, sometimes so quickly that people with MS don't know how they will feel from one hour to the next.

Many of these symptoms can be triggered by heat. They go away after the person cools down, but they can turn picnics, ball games or beach trips into nightmares.

Many people with MS want to ignore these weird symptoms as much as they can, and often they won't say much about them. They may try to dismiss them as Erin's mother does. "I feel my mom should take care of getting to the doctor and taking medicine, instead of acting as if it isn't important," Erin said.



Speaking up for yourself

One of the best things teens can do for themselves is to let others know what's on their mind and what they need. But what should you say and how should you begin? As Ashley said, "Everyone says, 'Talk about it; don't hold it inside.' But sometimes it's hard to get started."

Here are some ideas for opening up conversations with others:

Parent with MS

This may be the heaviest door to push open. You may be afraid to tell your parent about your worries or problems because you don't want to burden him or her. It's easiest to start a conversation at a time when your parent is comfortable and not too tired, and when you aren't too stressed yourself. Choose a time — when you're not arguing — and then plunge in. Tell your parent how you feel and what you think. Ask for understanding. Here are ways some teens have started conversations:

Needing Space

Beth felt smothered by her mother's constant requests. She approached the situation this way: "I love you, Mom, and I worry about you and about the future. I want to take care of you, but I can't be tied to you all the time either. I need



my own space, my own life." Beth then suggested some ways that her mother could help, such as making and keeping her own medical appointments and hiring a "mother's helper" a couple of days a week so Beth could be free to participate in school activities.

Wanting Thanks

Richie felt his mother took all the work he did around the house for granted and was feeling resentful. He opened up a conversation this way: "Mom, I'm happy to do whatever I can to make life easier for all of us. But sometimes I think you don't appreciate how much I do. It would make me feel so much better if you said thank you."

Getting Informed

Many teens feel left in the dark about their parent's condition. Myra wanted her father to be honest with her about the progress of his MS. She said this to him: "Dad, I love you and I worry about you. It would make me feel less anxious if you talked to me about what the doctor said. I'm old enough to be trusted."

Wanting an Apology

Rachel was upset at her mother's frequent lashing out at her because of mood swings. She said, "Mom, it makes me feel bad when you say hurtful things to me and then don't apologize later. It's OK to say, 'The MS made me do it,' and then say, 'I'm sorry.' I'll understand."

Even if your first few remarks are awkward or don't convey exactly what you mean, they can still open the way to future talks. If you can keep the lines of communication open, you'll eventually be able to say something like these other teens did.

Healthy Parent

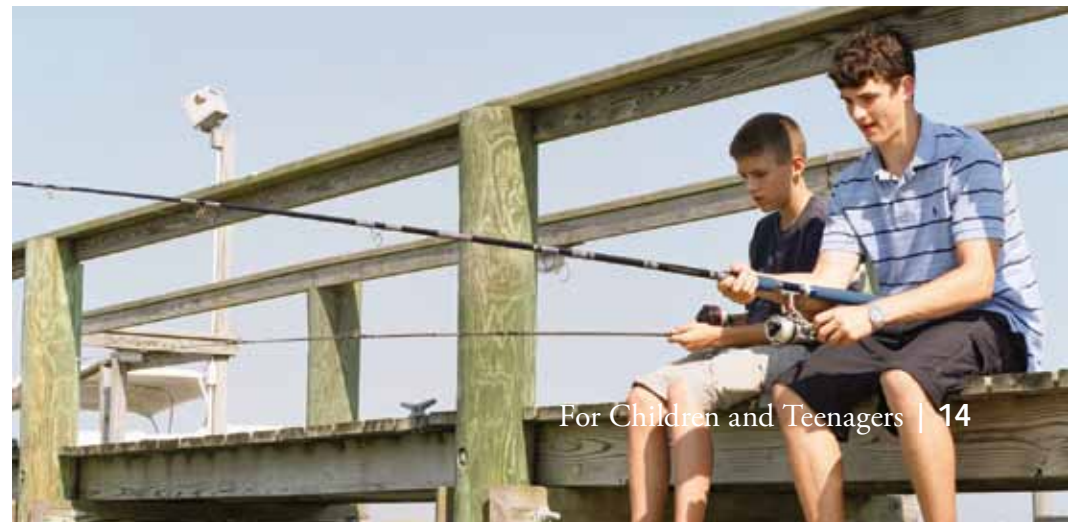
Whether your parents live together or apart, you'll find times when you want to talk with the one who doesn't have MS. Teens often wonder what's on the mind of the other parent, especially if he or she is the "strong, silent type." There may be a welcome surprise for both of you if you say, "Let's talk. I need to tell you how I see things and I want to know what you think."

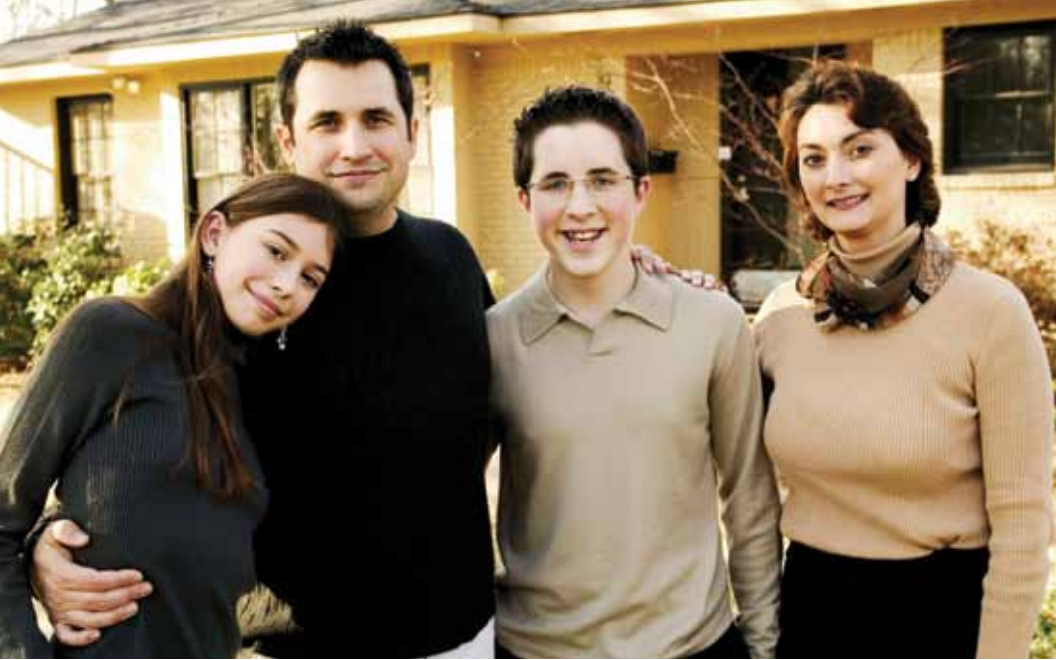
Of course, every parent is different. Some are just hard to talk to. Others are all over you with, "How do you feel? Why won't you talk to me more often?"

Whatever your parent's style, your best bet is to be honest about how you feel. If you're upset at the moment, it's OK to say, "I need to cool off. I'll talk to you in an hour." When you're calmer and ready to talk, just tell it straight. Of course, it's also OK to tell your parent politely that you'd rather not talk about something. You're entitled to your privacy.

Siblings

Talking with sisters and brothers is important too, but not always easy. Some brothers and sisters feel disloyal or guilty for talking about MS behind their parents' backs. Still, it can be very helpful to talk about the experiences you share. Even if you don't have heart-to-heart chats, brothers and sisters can at least talk about practical things, like how to divide up household chores fairly. Discussing potential problems before they boil over can prevent fights.





Strangers

When strangers stare or make rude comments about your parent, you may wish you had a snappy comeback. Unfortunately, there isn't one right way to handle this. Some people may just be deliberately cruel, in which case it's better to ignore them. Other times, they may be acting out of well-meaning ignorance. Your best bet is to sit down as a family and decide how to handle this. It's important to honor the feelings of your parent with MS.

Jeff, with his mother's approval, came up with this reply: "Oh, don't worry, she's not drunk; she has MS. Do you want to know more about it?"

Taking care of yourself

Your parent's MS has a big influence on your life, but the disease shouldn't dominate it. Your life can be happier if you live it as fully as possible. Here are some things that have worked for other kids.

Dealing with Strong Emotions

Anger is to be expected, and it shouldn't be hidden or denied. It is better to aim the anger at the MS and not at the person. In talking with the parent who has MS, it helps to explain how you feel and why: "I get mad when I have to do housework. MS really messes things up for me." This kind of statement directs the anger where it belongs — at the illness, and not at the parent who happens to have it. The opposite approach ("You were so mean to make me do the laundry!") doesn't help. It attacks the parent personally, makes him or her feel angry or defensive, and can leave you feeling guilty later.

Other emotions, like fear, sadness and shame, also need to be dealt with. Sort them out a bit, and talk to someone about them. If talking to a parent is hard, perhaps another adult you like would be a good listener, such as a friend's parent, youth group leader, family doctor, school counselor, favorite teacher, clergyperson, grandparent, aunt, uncle or older cousin.

Coping Strategies

Here are some things teens have said improved their moods and made them better able to deal with the tough stuff:

Write it down

Keeping a journal — just for you — can help you safely express all those thoughts swirling around in your head. “No one knows, but I write letters I never send, just to get my feelings out and to make me feel less alone,” said Heidi.

Get physical

Physical activity is the surest way to burn off anger and frustration. Run around the block, shoot some hoops, go for a swim, ride a bike, do yoga, play a team sport.

Get creative

Involving yourself in a creative activity puts your mind on other things. Paint a picture, build something out of wood (hammering is especially good!), take photographs, write a song, take part in the school play.

Relax

Having down time helps a person feel refreshed. Lie back and listen to music, catch some rays, read a book just for fun, breathe slowly and deeply.

Have fun

Call a friend and talk about something you both like. Play a video or computer game, watch a movie, go shopping, play with a dog or cat. What about a hobby?

Volunteer

Helping others takes people’s minds off their own problems. The National MS Society has many opportunities for teen volunteers, especially at Walk MS, Bike MS and Challenge Walk events. Visit Volunteer Match at volunteermatch.org to find out how and where you can help, or call your chapter directly at 800-344-4867 (800-FIGHT-MS). If you feel you need a “break” from MS, Volunteer Match lists many other volunteer opportunities.

Get a job

A part-time or summer job helps kids feel less dependent, especially if money is tight. But be sure to balance work time against time for school, home chores and social life.



Practical Solutions

These ideas could make life more manageable. Some you can do on your own; others will need your parent's help.

Use technology

Cell phones, beepers or “life net” call systems can give you some freedom while giving your parent a way to contact you in case of an emergency.

Schedule the chores

Set up a family calendar on the refrigerator so chores — and times off — are distributed fairly. Rotate the jobs that everyone hates so no one is stuck with them all the time.

Ask for help

If your parent's care needs are overwhelming you, or if you feel your parent is depressed no matter what happens (depression can be a symptom of MS as well as a response to its challenges), ask other family members for help. If you don't have siblings or another parent at home, ask relatives, even if they live out of town.

Getting Support

Many teenagers say that the best help they ever found was through support groups with other teens whose parents have MS. “I never knew that other kids had the same feelings about MS that I did. I thought I was the only one,” said Rachel.

The Society has offices all around the country. Some have teenage support groups and some have peer counselors. If you haven't connected with a chapter near you, call 800-344-4867 (800-FIGHT-MS).

If there's no MS teen support group near you, a school counselor may be able to locate a support group for teens whose parents have some other type of chronic disease or disability. While their experiences may not match yours identically, you'll have many common issues to share.

You can also check out one of these online support groups:

- msworld.org/html/chat.htm. This is the official chat site for the Society. It offers special interest message boards and a free e-mail group for family members of a person with MS to obtain e-pals.
- teenhelp.org. This free site is a network made up of peer mentors who offer support to teens on a variety of topics.

Counseling

If things are really tough at home, there are professionals who can help. Your chapter of the National MS Society will have a list of counselors or therapists in your area who have experience with MS. Be aware that a fee is usually involved for professional counseling. If money is tight, or if you don't want to enlist your parent in getting help, say so when you talk to the chapter. (See above for contact info.)

Looking Toward the Future

As senior year of high school approaches, some teens believe that they will have to shelve plans for college. They assume it will cost too much on top of medical and other family expenses or they may feel that they should not plan to attend a school away from home. But this may not be the case at all.

Talk with your parents and your school counselor. If college would have been in your plans without MS, you owe it to yourself to find out about college scholarships, loans, service programs and other alternatives. MS shouldn't hold you back.

To learn about the National MS Society's scholarship program, visit nationalMSSociety.org/scholarships.

The good stuff

Having a parent with MS isn't all bad. Even during rough patches when difficulties seem to overshadow everything, kids gain skills and experiences that their peers don't have. Here are some of the good things we've heard about that have come from having a parent with MS:

Gaining Competence

When teens do things like cooking, cleaning house, grocery shopping, yard work, laundry or handling power tools, they gain a sense of competence that their more sheltered peers don't have. "By the time I was 12, my cooking skills were legendary among my relatives and my parents' friends," said Larry. Now as an adult, his wife particularly appreciates his cooking skill. And, he added, "Some of the best memories I have are of cooking with my mother."

Feeling Important

Having responsibilities also helps teens gain a sense of importance to their family. They feel trusted, and that can make them feel more mature than their friends.

Helping Others

Seeing a parent endure MS can also give kids a strong motivation to help others. “Rather than letting my mother’s MS rule my life, I found a way to make a difference,” said Jennifer, who started a newsletter for children who have a parent with MS. “I wanted to help little kids feel hopeful, not hopeless.”

Volunteering doesn’t just benefit others. Miriam, who volunteered for Bike MS at the Mid Florida Chapter, said, “I have become a stronger leader from working with others.”

Many children of people with MS go into health care, education, research or social work — all highly valued careers that make lives better for others.

Respecting Differences

At a time when the pressure to fit in and be like everyone else is so strong, having a parent with MS helps many teenagers feel OK about being different.

Closeness with Family

Perhaps one of the best things about having a parent with MS is the closeness teens feel with their families. Often families pull together and help each other out. “I admire our family for how we handle things,” said Jeff.

“A lot of my friends come home to an empty house after school,” said Ashley. “I’m glad that my mom’s there when I get home. I’ve always got lots to tell her about my day. Plus, she’s good at helping me with problems.”

Your parent’s MS has a big influence on your life, but the disease shouldn’t rule it. By speaking up for yourself, taking care of your needs, and enjoying all the good things about your family, you can have a happy, full life.

To learn more about MS

Log on to our Web site at **nationalMSSociety.org**.

You can find out about:

- Breaking news in the MS world
- Symptoms, treatments and research on MS
- Educational programs, both live and on the Web
- Special events for teens and families in your area
- Volunteering opportunities near you
- Webcasts where experts talk about specific MS problems
- National MS Society scholarships

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your physician.

The Society publishes many other pamphlets and articles about various aspects of MS. Visit nationalMSSociety.org/brochures to download them, or call your chapter at 1-800-344-4867 to have copies mailed to you.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at nationalMSSociety.org or 1-800-344-4867 (1-800-FIGHT-MS).

Some of our popular pamphlets include:

- **Plaintalk: A Booklet About MS for Families**
- **Living with MS**

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