

Keep
your

Balance!

Teens talk
about living with
a parent with
multiple sclerosis



Multiple
Sclerosis
Society of
Canada

Second edition



Insights and
information
that can
help you cope.



Comments and
personal stories from
teens living with
a parent with MS.



Relationships that can bring
you strength, understanding,
support and respect.



Keep your Balance!

Teens talk about living with a parent with multiple sclerosis

Multiple Sclerosis Society of Canada 1998 and 2006.

"Keep your Balance!" is a collection of testimonies from adolescents who have a parent with multiple sclerosis (MS). The teenagers express their feelings and recount their experiences of living with MS in their families. These testimonies were collected during a workshop organized by the MS Society and through a questionnaire sent to families who have adolescents. Twenty adolescents and their families and friends participated in this project. Their stories tell of the adjustments they each had to make when faced with common and sometimes unique situations that MS brought to their lives.

This book is written for adolescents to help them better understand their feelings about MS. It can also serve as a communication tool between parents and teens, or to initiate group discussions using the themes of the book. Information on MS and suggestions for activities are also included. This book may be helpful for other family members, relatives, friends, educators, or anyone who wishes to better understand adolescents who live with a parent who has MS.

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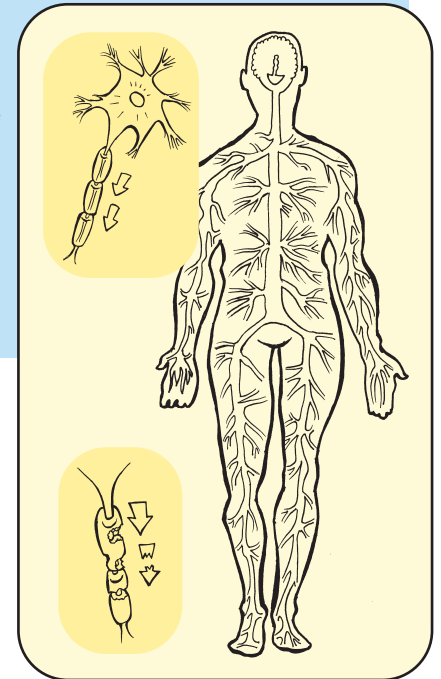
What is MS?

Information on

MS is a disease that may affect the brain, spinal cord and optic nerves (central nervous system). Think of the brain as a computer that sends messages to your body telling it what to do, while the spinal cord resembles a thick cable of wires attached to the brain. Messages travel from the brain along the spinal cord to the nerves and muscles throughout your body. When these messages are distorted or disrupted by MS, a wide variety of symptoms may occur.

What happens in MS?

Researchers believe that an immune system attack affects myelin, which is the coating that protects the nerve fibres of the central nervous system. Damaged myelin may form scar tissue (also called 'lesions', 'plaques' or 'sclerosis'). Scar tissue on the myelin can block or slow down the messages being sent along the nerves. So when the brain tells the arm to wave, the message may not be clear, or it may never reach the arm at all.



What is the cause of MS?

We do not know as yet what causes MS. There is some evidence that MS may be triggered by a common virus, but we also know that genes play a role in the development of the disease. There is no evidence, however, that MS is a directly inherited disease. The vast majority of people with MS do not have a first-degree relative (parent, sibling, etc.) with MS.

Who gets MS?

- **Women are more than twice as likely as men to develop MS.**
- **MS is most often diagnosed between 15 and 40 years of age. Children and older adults can also develop MS, although this is less common.**
- **MS is seen most commonly in people of northern European background.**

What are the symptoms of MS?

Symptoms vary greatly from person to person and from time to time in the same person. They also vary in severity and duration. Many of the symptoms are invisible, so it may not be possible to tell what someone is experiencing just based on appearances. MS symptoms might include:

- extreme fatigue
- dizziness
- weakness
- numbness and prickly feelings
- blurry or jumping vision
- speech problems
- loss of coordination or balance
- need to urinate without delay
- mood changes
- temporary loss of ability to move arms or legs
- pain in a body part for no apparent reason
- irritability
- depression
- headache
- constipation
- poor memory for recent events
- inability to make decisions quickly

Remember, the majority of people with MS do not have all these symptoms.

Multiple Sclerosis (MS)

What are the different types of MS?

There are four main types of MS:

RELAPSING-REMITTING MS

characterized by clearly defined relapses (when symptoms appear or get worse – also called ‘attacks’ or ‘exacerbations’) followed by complete or partial recovery called remissions (when symptoms disappear or are not as severe). This is the most common form of MS.

SECONDARY-PROGRESSIVE MS

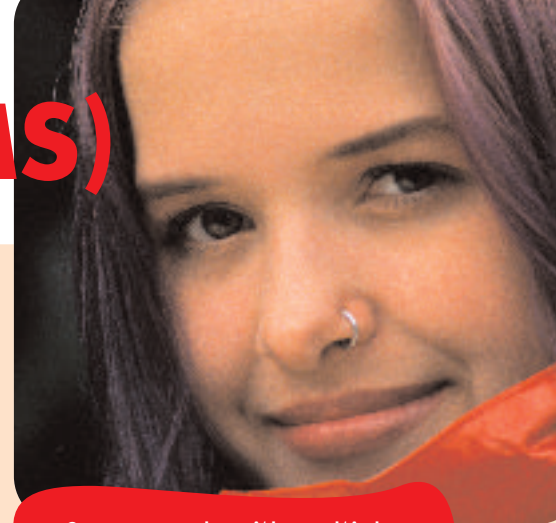
about half of people with relapsing-remitting MS start to worsen within 10 years of diagnosis, often with increasing levels of disability;

PRIMARY-PROGRESSIVE MS

less common, people with this type of MS have a nearly continuous worsening of symptoms from the beginning usually without clear relapses or remissions;

PROGRESSIVE-RELAPSING MS

relatively rare, combines relapses with steady worsening from the beginning of the disease.



Some people with multiple sclerosis find that the disease affects very little their day-to-day life. Others with a more progressive form of MS will find that many aspects of their life are affected. The important thing to remember is that people with MS can have a full and productive life, despite the difficulties the disease may bring.

Are there treatments for MS?

Thanks to research, there are now several drugs available for people with MS. These drugs can help slow down the frequency and the severity of MS relapses. They may also slow the development of disability. Therapies which help MS symptoms are also available.

Is there hope for a cure?

Absolutely. Since the 1990's there has been a remarkable increase in what we know about MS. More than 2,000 research papers about MS are published every year. The MS Society and its related MS Scientific Research Foundation are continuously funding research projects to find a cure for MS.

Clearing up misconceptions about MS

- It's not a mental illness.
- It's not contagious.
- It's not considered a fatal disease. Most people with MS can expect to live a normal or near-normal life span.
- It's not directly inherited, although studies show that there are a number of genes that predispose to the development of MS. The vast majority of people with MS do not have a first-degree relative with the illness.
- Although many people associate MS with being in a wheelchair, studies show that approximately 70% of persons diagnosed with MS will not require wheelchairs on a permanent basis.



Dealing with MS in the family

MS is an unpredictable disease. We cannot anticipate its symptoms or progression, and this makes it hard to know what to expect. Learning that your parent has MS can open up a flood of emotions, such as shock, denial, fear, anger, frustration, depression or guilt. It is understandable that you should have such feelings. Teens of a parent with MS have to put up with a lot more than their peers with healthy parents. Respect your own coping mechanisms: some people find learning about MS helpful, others find that talking about it helps them through difficult moments. Others choose not to talk about it at all. Some get involved with the local MS Society chapter. There is no one way to deal with an illness such as MS.

When I **found out** about the **diagnosis**

When you learn that your Dad or Mom has MS, it's normal to feel all kinds of emotions and to have many questions. Sometimes just getting the facts about this disease can make things easier. Don't hesitate to find out more about MS and ask all the questions you have. It's also important to talk about your feelings to your family or friends. You can call the Multiple Sclerosis Society of Canada to get information on MS. The more you know, the more you will feel comfortable talking about the disease and living with a parent who has MS. Call the nearest MS Society Division office at 1-800-268-7582 or check our website at www.mssociety.ca.

I was nine years old when my Mom got sick. Nobody told me what she had. I saw she wasn't well. I had many questions and wondered if she would stay sick or get worse. I was really scared.



When I found out that my Dad had MS, I was in junior high school and about 13 years old. My reaction may have seemed cold for someone who doesn't know me. But inside of me I felt totally helpless, sad and really upset. I didn't know whom to turn to. My parents were really worried, so I just kept everything inside not to burden them. For two years, I just didn't really want to talk about it. Then my Mom suggested I see a counsellor. That really helped me sort things out.

Annie, 17 years old

When I found out, I felt really strange. I didn't know how to react. I was frustrated, upset, angry, really mixed up. I felt all kinds of emotions inside of me. In my head, my Mom was obviously about to die. In seven or eight months, say, she would be paralyzed and maybe she would spend 10 or 11 years sick in a hospital and then die, finished, kaput. Then time passed and I saw that it wasn't really that way, and that she was doing okay.

Peter, 18 years old

My Mom calmly told us that Dad was sick and explained about his illness. We were upset to find out and we all cried. I think that when you learn that someone you love very much will be sick for the rest of their life, it's really sad. We don't know how he'll be in the future because MS is different from one person to another. Money was also a worry for us because my Dad didn't know how long he could continue working.

Bianca, 19 years old

What has MS changed for me?

As he grows older, my Dad's illness is getting worse. He now needs a walker to get around and the house is adapted for him. It makes me very sad. I don't dare to talk to him about my problems because I know he has bigger problems than I do. I don't blame him because he didn't ask to be sick. I think MS has brought us closer together. He has more time for me, which is fun, when he was well he would always be gone somewhere and too busy for us.

Nadine, 16 years old

My Mom started a treatment for MS about a year ago. At the beginning I didn't like it, my Mom had to inject herself every other day and I thought she was like a drug addict. Now I feel okay about it. Sometimes I do her injections myself. I don't feel she is really different than any other mothers.

Sarah, 12 years old

I find it difficult to deal with my Dad's disease. He doesn't accept being sick. He feels useless and thinks that he doesn't really count for us. This makes me really sad. It's like he feels guilty that he can't work anymore and without realizing it, he's mad at my Mom who can still work. That often creates tensions in my family and that upsets me. I even find myself angry with him, which makes me sad because I know he's not acting that way on purpose.

Isabelle, 18 years old

MS can change a lot of things for you. Getting to places may become more complicated and unpredictable. Your family may not be going out as much as you used to. You may have more chores at home. There may not be enough money in the family for extras, such as music or sports lessons, new clothes, or the movies. Sometimes you might think the roles have been reversed and you may suddenly feel like the parent. Don't feel like you have to act as if everything is okay if it's not. Ask for help from people around you who are either members of your family or friends or speak to a school counsellor or a family doctor. Everyone needs support from time to time. Having a parent with MS is not all bad. You may find yourself gaining skills and experiences your peers don't have, like a sense of competence and independence, a greater feeling of importance in the family, and a more caring attitude towards other people's problems.

Sometimes we get ready to go to a party, then, at the last minute, she doesn't feel well and we have to cancel. I find this very disappointing. When that happens, I think to myself that it's a drag, I can't go and I'm missing something. But then I tell myself that we can go another time when she's feeling better. Maybe another time, we'll have an even better party than the day when she wasn't feeling well.

Jennifer, 13 years old

Right now, my Dad can't walk at all or get up by himself. He can hardly hold something in his hand. It's another exacerbation. Lately, he's been in the hospital twice for about a month each time. Despite all that, I'm proud of him and think he's brave, because he has kept his smile and good humour through it all. He is a father who cares about his family no matter what.

Anne, 17 years old



Relationship with my parents

“I feel more independent since I do more things on my own.”

Nicolas, 18 years old



My relationship with my Dad was rather special. We were very close and always went places together. And then the illness changed things. We can't go out and do the same activities as before. But he is still and always will be my Dad. I wish my Dad wouldn't be so proud though, then I could help him more. It's hard when you want to help and he doesn't want you to. I'm happy that despite his illness, we still have a great relationship. It proves that even if he can't stand well anymore, he can be a great Dad for me.

Anne, 17 years old

I know when he's not feeling well and I tell him: "Dad, why don't you lie down for awhile?" My Dad is still working and he is running around all the time. He's pretty active. I tell him "Go rest for awhile, I'll take your place." And he goes, he listens to me!

Julie, 15 years old

My Mom gets upset quite easily now. That means many arguments. Sometimes I'd like to pack a suitcase and leave. And then my Mom says "Come here, let's talk." We each have our say and we're always able to work things out. I've never felt like leaving and not coming back. Everything gets worked out and we get along really well. I feel very close to my Mom but with my Dad it's different. I'd like my Dad to understand what I'm feeling. We don't talk enough.

Jennifer, 13 years old

I know that my Dad suffers but at least he talks about it. It bothers me that my Mom doesn't want to talk to me about it. For her, there is no problem. Everything is wonderful and she never talks about it. She is very sensitive but finds it difficult to open up to us.

Bianca, 19 years old

When we are under stress, we get angry more easily. Mood swings and irritability are common for someone who has MS. Your parent may be upset that he or she has this disease. MS may prevent you from doing some things making you feel angry or helpless too. One of the best things you can do for yourself is to let others know what's on your mind and what you need. You may not want to tell your parents about your worries and problems because you don't want to burden them.

Research has shown that sometimes parents tend to underestimate the impact of MS on their children. Talk to your parents about the changes MS brought to your life and how these affect you. It's easier to discuss things when you and your parents are calm and rested. Tell them what you feel and what you think and ask for their understanding.

My Dad has practically no time for himself. He has to look after my mother which is a big responsibility. Since she's been sick, my Mom has been less patient and has a bad temper. Sometimes I lose patience and get angry too.

Daniel, 12 years old

My Dad will always be my Dad even if he can't do the same things as before. I love him and I respect him.

Carl, 16 years old

My relationship with my Dad is pretty close right now. I don't think that MS has a direct effect on that.

Certainly when my Dad is more tired, he loses his patience more quickly, but then I'm often on edge too. Sometimes we'll fight for no reason, about really dumb things. I think he is aiming for an ideal about things that he wasn't able to do, or that he used to do and would like me to do. I have to make my own mistakes and experiences. Sometimes he tells me I don't need to go through those mistakes because he's done them. I find my Dad brave and I know that he's made a lot of sacrifices for me. He keeps a good sense of humour and is able to joke about things.

Although he isn't able to run around and he feels like he's not perfect, when he has a relapse, he keeps his spirits up and I've never seen him fall apart. We have a strong family spirit; we stick together and help each other out. That creates solid bonds.

Louis, 14 years old

Parents talk about the changes

Nothing has changed, nothing. It's just an illness, it's just my body that is affected and not my love or my ability to listen to him.

A parent with MS

I am more demanding. I insist that she helps her mother. I ask her to do more than before because I'm often away.

A parent without MS

My relationship with her hasn't really changed. Sometimes we're more sensitive to each other's limits and weaknesses.

A parent with MS

“It's getting better and better. She was very far away from me. Now, she's closer and even confides in me sometimes.”

A parent without MS

What is difficult is when I feel he is ashamed of me in public because of my wheelchair.

A parent with MS



What I appreciate about my teen

His attitude and behaviour, for example he never hesitates to give me his arm to help me get around.

A parent with MS

His very good attitude and understanding that certain activities may change.

A parent with MS

I really appreciate her attitude on the rare occasions that we go out together (my husband, daughter and me). She is more than a help for me, she supports me. I appreciate the help she gives me personally in doing household chores and just the fact that she is there for me. She's often the one who brightens my days by her presence and even sometimes by her bad moods.

A parent without MS

Relationship with my brothers and sisters

Sometimes, my brother or I find things difficult and we worry. We find it hard to see my Dad suffer. But often we can talk about it together.

Jackie, 15 years old



My brother doesn't react at all like me. Since he is quite extroverted and I'm introverted, we don't really talk much. I find it difficult but it must be worse for my brother. He has always missed having my Dad around and hasn't been able to do activities with him and that has affected him a lot. I get along quite well with my brother except that we don't communicate enough. We don't do the same activities, so we're not close, but you know we love each other.

Nadine, 16 years old

I helped my sister understand what MS is. She knows she can count on me. When my little sister saw my Mom like that, she started to cry and then she didn't want her to go in the hospital. I said that it will be okay after she goes to the hospital, she'll get better and better and she won't always stay there, she'll come back. And then my little sister felt better.

Jennifer, 13 years old



A brother or sister can be very supportive. It's not always easy to talk to them, especially when you feel like you might be talking behind your parent's back. Even if you don't always feel the same way about things, you can still help each other either by talking about what you're experiencing or by sharing the chores that need to be done.

During the most difficult period, we didn't help each other much. It was after Dad left for the Rehab Centre that we realized that we had to bring out in the open what we were thinking.

Lynn, 17 years old



Relationship with my relatives

My grandfather helps my Dad a lot. He often comes to see him. My uncles and my aunts want to help but can only do a little. Like us, they feel a little helpless.

Bianca, 19 years old

I don't talk to them but they come and talk to me. It helps me sometimes.

Caroline, 15 years old

The family helps a lot. They make supper for us and do errands.

Daniel, 12 years old

My brother, my sister and I are close and we help each other. We fight which is normal in every home, but we love each other a lot.

Bianca, 19 years old

I've been closer to my sister since Mom has been sick. She comforts me and can explain things to me about MS. When she's the one who's sad, she thinks I can't help her though.

A little sister

He confides in me and I try to understand.

A big brother

I set an example and explain things to him.

A big brother

Sometimes it's easier to speak to an uncle, aunt, or cousin than to your parents. Also, occasionally, your relatives can help out and suggest ways to make your life easier.

“In my Dad's family, they have difficulty accepting his illness.

Especially right now because my aunt who had MS died not very long ago. In my Mom's family, they're worried about the illness and also ask a lot of questions.”

Jackie, 15 years old



Relationship with my friends



Friends are very important to any teenager. Explain to your friends what MS is and they will understand better what you're going through and might even help you out sometimes. Talking to your best friend about your emotions and feelings can take a load off your shoulders by giving you strength and understanding. But remember, it is your choice whether and when to tell people about your parent's diagnosis.



“When I talk to them sometimes, I don't think they understand but I know they're trying.”

Jackie, 15 years old

I think it would be great if everybody had at least one person to talk to, confide in, and tell their frustrations and deepest feelings to. Regardless of whether the illness bothers you or not or whether you like it or not, you have to get it out somehow because you can't keep all of that inside you - it's not healthy.

Anne, 17 years old

Nothing has changed with my friends and my boyfriend. After all, it's an illness like any other.

Julie, 13 years old

Last year, I had a friend who was my best friend. We talked about everything: good times, bad times, our parents. He understood me. I could tell him a lot of things. He knew what I was thinking about.

Marc, 12 years old

I get along well with my friends but my love life is lousy. But that's not the fault of MS! If my Dad's MS ever became apparent, I wouldn't be embarrassed. One of my friend's father had a bad accident, he's in a wheelchair now. I realized that my Dad is pretty cool. So why should I worry about bringing friends home? I wouldn't be embarrassed because he's in a wheelchair.

Alexander, 17 years old

My friends' reaction to the diagnosis

I asked her some questions and we continued to talk. Nothing has changed between us. She has a sick parent but she's the same as everybody else.

A friend, 15 years old

I heard about the diagnosis five years ago. At first, I didn't really understand what it meant but I found out from my friend.

A friend, 15 years old

I felt lonely at first. When all my friends got together, I was with them but I felt alone. I began to talk to my friends and now they understand me. When my Mom is in the hospital, I worry a lot and that's when I talk to my friends. They tell me that things will get better and work out for the best and that gives me a lot of courage.

Jennifer, 13 years old

When I invite friends to our house, I warn them from the beginning, I tell them what it's going to be like. That way, they know what's coming and don't ask as many questions. I tell them so, if they're not happy, too bad that's the way it is and I have to live with it. Most people don't mind.

Julie, 15 years old



No, nothing has changed. She wouldn't like anyone to pity her. I think about her in the same way as anybody else.

A friend, 15 years old

He has taught me what MS is and to understand that for those who have a family member with MS, it's not always easy.

A friend, 13 years old

How friends can help you

I think that the day I helped my friend the most was when her Mom went into the hospital because of an MS attack. I tried to be there for her.

A friend, 13 years old

The advice I have to give to her is don't give up because life is beautiful.

A friend, 15 years old

I just want to tell my friend that I'll always be there for her.

A friend, 13 years old



What I find **difficult**

Teens of parents with MS may have to put up with more than their peers with healthy parents. You may have more chores around the house, you may have to deal with the unpredictability of the illness, money strains, and sometimes a lack of understanding for what you are going through. Asking for help doesn't mean that you are weaker than or not as good as someone else. On the contrary, it proves that you are smart and brave enough to get what you need. If you don't know who to talk to, you can call the MS Society of Canada or pay us a visit.

Decisions are always made taking into consideration my Dad's MS so we can't make our own decisions. Sometimes I find it unfair. You have a lot of plans and you want to go out but you can't because you have to think about him. Is he well enough to go out tonight or too tired? The most difficult times I have experienced are when my Dad falls down and I have to get him up. It's embarrassing for him and for me.

Nadine, 16 years old

My Mom has to stay at home and that makes her feel sad and me too. Sometimes I can't sleep because I worry too much. I feel responsible. I'm more depressed than mad and I'm worried about her. That's what I find most difficult.

Daniel, 12 years old

“It's hard when I see she's tired. She's very proud so she continues her activities with difficulty until she's completely exhausted.”

John, 17 years old



I think the most difficult thing is when other people ask me questions like “What's wrong with your mother, why is she using a cane?” At least when I explain they understand.

Emily, 12 years old

What bothers me the most about my Mom's MS is that whenever she has an attack, she's in the hospital for at least a week. I feel a little alone and I wonder how long will she be there. I don't feel like doing anything when she's in the hospital. I am grumpy at school. My friends ask what's with me. “Nothing!” I say, like I'm fed up but it's because my Mom is in the hospital. It worries me to think that she might have to go back again.

Jennifer, 13 years old

The thing about this disease that affects me the most is not so much the fact that he's sick and he can't do as much stuff as before. I'm upset and I worry a lot because I know that my Dad's morale is suffering. He was so active before and now he's stuck in a wheelchair all year long. He's less independent and hates asking people for things. He has lost a lot of self-confidence and that brings on his mood swings. He's more impatient and so are we. Because of this, there is often tension in the house. We each have our little problems and moods. Other than listening and understanding him, I can't really help him.

Bianca, 19 years old

What helps me cope

What helps me get by is the closeness between my parents, my sister, my brother and I, as well as my activities and a friend I can talk to.

Bianca, 19 years old

If I'm worried, I tell my Dad and then we talk. But I don't worry very often, so I haven't talked to him about it much. We don't talk about MS very often but when we do, we talk openly. I relax by playing the guitar. When I'm feeling sad, I play a sad tune. Sometimes I play computer games.

Alexander, 17 years old

I did some research on multiple sclerosis last year for an oral presentation. I know a lot about MS now.

Jackie, 15 years old

Your life shouldn't only revolve around your parent's MS. It's important to find a balance between your needs and your family's. Take the time to do the activities you enjoy. These activities can act as a valve for the emotions you're experiencing. A part-time job can get you out of the house and allow you to forget MS for awhile. Getting involved as a volunteer can help you find a job later. You will also benefit from a boost in your self-esteem and gain valuable experience. A lot of feelings, ideas and solutions can be shared with other young people who, like you, have a parent with MS. Between friends, you can give each other the support and encouragement you need. You can also help other people yourself. Some of the MS Society's activities facilitate these kinds of encounters. Find out about them from your local chapter.

What helped me the last time Mom went into the hospital was that we often went to visit her. I could see her a lot, so it wasn't so bad. We know it's not going to be for long and we tell ourselves that she's going to get better so that helps us.

Jennifer, 13 years old

When I have problems with my Dad or when things aren't going well, I try to get away to forget what's going on. I do something to unwind such as rollerblading, but sometimes I just stay in my room. I try to wait until it's blown over and then come out when things have cooled down. That avoids conflicts, anyway.

Louis, 14 years old

I received a lot of information about MS - a bit late but I did get it. That helped a lot. It's important that parents don't hide what's going on, so children have the time to adjust to the changes before they happen.

Lynn, 17 years old

Here are a few ideas that other teens found helpful in coping with MS:

- **Keep a journal** – write down your feelings and thoughts;
- **Be creative** – make a video on MS, work on a collage on themes found in this book; do a research project or a presentation on MS for a school project;
- **Get active** – play sports, go on a hike or go for a walk with your friends – this way you'll manage to stay fit and burn some of the anger you may feel;
- **Stay informed** – check out websites and other resources on MS to learn more about the disease;
- **Relax and have fun** – it will help you feel refreshed;
- **Reach out** – meet other teens who have a parent with MS through some activities organized by the MS Society or exchange e-mails or letters with them;
- **Get involved** – volunteer, participate in fundraising events of the MS Society or initiate a fundraiser yourself. Helping others takes people's minds off their own problems.

Parents speak out – what helps teens cope?

What helped her cope the most was meeting other teens who had a parent with MS at a family event. She realized she was not the only person to live with a parent who has MS and realized she was lucky that I'm hardly affected.

A parent with MS

Communication is important; we have to explain how we feel today and have a positive attitude towards the future.

A parent with MS

The good times



It seems strange but the illness has had a positive effect on us. My Mom takes better care of her health now. She's realized for her sake and mine that her state of health could deteriorate suddenly. It's impossible to know when. So she's taking advantage of the present and I'm doing the same. I prefer living each day to the fullest, not worrying about the future but really being happy and enjoying simple things because you never know what can happen later. We take care of each other.

Bianca, 19 years old

I have quite a few good times with my Dad. Fishing is an activity I enjoy with him.

Alexander, 17 years old

When we get together for a family meal, it's fun. We like to play cards or board games. Sometimes we cheat a bit to have more fun!

Jennifer, 13 years old

The whole family laughs a lot. We do all kinds of activities together. We go to the movies, shop and have lots of fun.

Jackie, 15 years old

It is important

to enjoy good moments with your family. Even if activities have changed, there are still a lot of nice things you can do together. You only need some imagination and good planning. Keeping your spirits up and good humour can go a long way in helping you stay happy.

Parents talk about the good times

Since I don't work anymore, I'm more relaxed and we have more time to talk. She likes to know that I'll be there when she comes home from school.

A parent with MS

While I'm on sick leave, I have more time for him. We can swim in the family pool, rent a good movie and watch it together.

A parent with MS

"I like to play chess or listen to jazz music with my Dad. He is a real fanatic!"

Louis, 14 years old

Brothers and sisters tell about some good times

There are a lot of them. When we go out, we have a lot of fun.

A little sister

We have a lot of fun at mealtime. We tell jokes and laugh at ourselves.

A big brother



Some wishes from parents

I'd like her to appreciate each moment, enjoy the pleasures of life by living intensely and being happy in all her endeavours. I love her very much.

A parent with MS

I hope she can accept herself as she is and thus see life differently. I also wish that her father's MS will continue to open her heart to others. My expectations for her are the same as those of all mothers for their children except that sometimes I'd like to be able to depend on my daughter without having to explain why. She knows or almost knows what I'm living on a daily basis. Are these expectations reasonable or a dream?

A parent without MS

I hope that they blossom and become independent and that they work seriously at their studies while having fun in their leisure time.

A parent without MS

I wish that she could be more positive and emphatic with people and that she continues to be involved in her activities outside the family. I hope she'll be happy and that we can talk more often whenever she's worried or sad.

A parent with MS

Life is wonderful; it all depends on which way you look at the glass: is it half full or half empty?

A parent with MS

If I could change something...

If I could change something in my life, I would certainly change my Dad's illness. I'd like him to be able to walk and do activities like other people. I wish that other teens in the same situation would not lose hope. I'd like teens to talk more openly about their fears and hopes.

Nadine, 16 years old

I'd like to change my Dad's bad moods, so that he'd not complain so much.

Alexander, 17 years old

I'd like my Mom to be well enough to do activities with me and walk again.

Caroline, 15 years old

I would like to be more patient.

Nicolas, 18 years old

"I'd like to have some money. My Dad could live with us in a pretty house, specially adapted for him. Right now, the nursing home costs us so much that we don't have much left at the end of each month."

Lynn, 17 years old

I'd like to have some money to be able to spoil my Mom and my Dad. They've done so much for me.

Luke, 18 years old

How I see the future

I'd like to become an actor, have fun and make lots of money. I think that I'll have trouble leaving my Dad and Mom later. My Dad will be older and it will be more difficult for him to look after my Mom. I hope they can find a cure or something.

Daniel, 12 years old

Next year, I'm going to take social work at university. After what I've been through, I think I can help others overcome different obstacles in their lives.

Lynn, 17 years old

In conclusion

Hope is a powerful life force that sustains us. And the marvellous thing about hope is that it is contagious.

You should never lose hope! You have to stay self-confident, keep smiling, put your best foot forward, and fill your heart with hope!

Anne, 17 years old

When one door closes, there's another door that opens. You just have to try and keep on trying.

Julie, 13 years old

It scares me. Soon we're all going to leave home so my parents won't have as much help around the house. I'm worried about the future: my Dad's health, physically and

emotionally. I'm worried about the relationship between my Dad and my Mom.

Bianca, 19 years old

Later, I'll work and have a family after I've finished my education. Maybe my Dad will be in a wheelchair but I hope with all my heart that before then a drug will be found to cure or stabilize the disease.

Jackie, 15 years old

Our future will be like any other family's. We'll be an ordinary family. Somebody may get sick. Or an illness may get worse. It's like any family. Anyone can suddenly get sick. I'll just take it one day at a time.

Alexander, 17 years old

Sometimes mothers say that children are their most precious possession in the world. For me, my Mom is the most precious thing I have. That's why I try to take advantage of every moment we spend together.

**Bianca,
19 years old**

There may be many things you are planning for your future: going to university, having a family, a career, etc. Whatever plans you have in mind, remember that despite your parent's MS you owe it to yourself to explore all the possibilities to make them happen. Discuss with your parents or other adults you trust. Together you may be able to find ways to overcome some obstacles in your way in order to realize your dreams.



Resource Guide

About the Multiple Sclerosis Society of Canada

The Multiple Sclerosis Society of Canada is a national voluntary organization founded in 1948. Its mission is: To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

The MS Society offers information, referrals, programs, educational workshops, equipment assistance, self-help groups, social and recreational activities, opportunities to get involved in fundraising, and more.

The MS Society has a number of booklets and videos on MS that are available free of charge upon request. Contact the closest division office or your local chapter to inquire about these. If you have any questions about MS, call us or e-mail us and we will get you the information you need. Check our national website or the website for teens of parents with MS.

Call toll free: **1-800-268-7582**
Email us: **info@mssociety.ca**
Visit our Website: **www.mssociety.ca**

Other online resources:

MS Society's website section for teens:	www.mssociety.ca/en/help/iAmaTeen.htm
Let's Talk MS – For Teens (English only):	www.msforteens.com
Teens inside MS (English only):	www.nationalmssociety.org
Let's Talk MS – For Parents (English only):	www.msforparents.com

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The Multiple Sclerosis Society of Canada is an independent, voluntary health agency and does not approve, endorse or recommend any specific product or therapy but provides information to assist individuals in making their own decisions.



How to reach the Multiple Sclerosis Society of Canada Current as of July, 2006

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info@mssociety.ca

NATIONAL OFFICE

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Suite 700, North Tower
Toronto, Ontario
M4W 3R8
(416) 922-6065

ALBERTA DIVISION

Victory Centre
11203 - 70 Street
Edmonton, Alberta
T5B 1T1
(780) 463-1190

ATLANTIC DIVISION

71 Ilsley Avenue, Unit 12
Dartmouth, Nova Scotia
B3B 1L5
(902) 468-8230

BRITISH COLUMBIA DIVISION

1501-4330 Kingsway
Burnaby, British Columbia
V5H 4G7
(604) 689-3144

MANITOBA DIVISION

Suite 100, 1465 Buffalo Place
Winnipeg, Manitoba
R3T 1L8
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ONTARIO DIVISION

175 Bloor St. East,
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