



Multiple Sclerosis  
Society of Canada

# Growing Up Strong: Supporting the Children of Parents With Multiple Sclerosis

## Overview of the Survey Results

May, 2003



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## Acknowledgements

This report was prepared by Meredith Associates and Cristina Toporas, Project Manager, for the national project *Growing Up Strong: Supporting the Children of Parents With MS*, managed by the National Client Services Department of the Multiple Sclerosis Society of Canada.

We would like to thank the *Growing Up Strong* Advisory Committee members for their valuable feedback on this report.

## 1 Introduction

In the drive to support the day-to-day efforts of people with MS and to find treatments and a cure for the disease, it's easy to forget those who are affected by the disease even if they do not have MS themselves. Children of parents with MS in particular may suffer both emotionally and practically.

In response to that concern, the MS Society of Canada launched *Growing Up Strong: Supporting the Children of Parents with MS*, a two-year project funded through a generous grant from the Population Health Fund of Health Canada. The objectives of *Growing Up Strong* are to develop, evaluate and deliver integrated services and programs nationwide for children aged 6-18 who have a parent or parents with MS. These programs and services will address the unique educational, emotional, social, and physical needs of children of parents with MS.

In 2002-2003, as part of *Growing Up Strong*, the National Client Services Department of the MS Society conducted a survey of parents and children to identify areas where additional programs and support would be beneficial for children of parents with MS. This document is an overview of the results.

## 2 Background

In an earlier stage of *Growing Up Strong*, the MS Society conducted a literature review identifying the needs of children of parents with MS. The findings of the literature review show an overwhelming conclusion that more research is needed about the children of parents with MS.

The literature review also indicated that parents and children often held different views on the needs of children of people with MS. Existing studies and discussions with researchers suggested that adult children of parents with MS and children aged 12-18 could also have different perspectives.

Based on the findings of the literature review, the project team decided to develop and conduct a national survey on the needs of children of parents with MS.

## 2.1 Family strength

A decision was taken in building the survey to develop a strength-based approach rather than focus on needs and deficits. A review of studies related to early years development, children of deaf people, people with mental health challenges, and arthritis highlighted needs similar to the needs of children of people with MS (*List of studies – Appendix 1*). This encouraged the research team to recognize that many of the needs of children of people with MS are universal needs of children that may be affected by family-related factors in addition to disability- and disease-related factors. Based on research in the United States and Australia by Defrain et al., it was suggested that families that had different approaches to working together would have different perspectives on the impact of MS. In other words, family strength was a key issue in how a parent’s MS could affect the children in the family.

The approach taken in this survey is a strength-based model (building on the asset-based community development model of John McKnight et al.), using the perspectives of the people affected by MS to identify what they believe is important for their children and other children affected by MS. The purpose of the strengths-based approach is to recognize and reflect to participants that families generally develop strategies to address many concerns – and to learn from these.

Another part of the approach was not to undermine the situation of families with MS by focusing solely on the negative aspects of the MS. Using these results from this perspective is likely to create resonance with people affected by MS – showing strategies that work to support children to grow up strong – because most people want their kids to grow up strong. As a result, a number of questions were asked about the family to determine whether families have characteristics of strong families.

The data has been analyzed comparing the views of “strong” and “weaker” families. The determination of whether a family was strong or weaker was based on a self-assessment by each person based on their agreement with the statement “Overall we are a strong family.” This analysis enables the identification of the different strategies used to support children in strong families compared to weaker families.

### 3 Methodology

The overall survey process included:

- A set of three **questionnaires** designed for three separate groups: children aged 12-18 of parents with MS, adult children of parents with MS, and parents. (*Appendix 2*)
- A series of **focus groups** for children aged 6-12 of parents with MS.

Participation in both parts of the process was voluntary. The survey was designed to be a self-selected convenience sample of people generally known to the MS Society. Because of this, the sample likely includes a number of biases (where people live, age groups, gender, proportion of different family members, etc). The information reflects the views of the people who responded.

#### 3.1 Questionnaires

The questionnaires gathered the views of parents with MS, their partners, children aged 12-18 of people with MS, and adults whose parents had MS when they were children. The information has been analyzed for each of these groups.

The questionnaires were publicized through:

- 3,500 flyers distributed to MS Clinics across Canada
- Local, regional and national MS Society publications (*MS Canada* only has a circulation of 30,000)
- MS Society web site

Chapters and Divisions of the MS Society were also encouraged to distribute flyers and information on the survey at their events (conferences, meetings, etc.).

It should be noted that because of the way the questionnaires were distributed, most of the questionnaire respondents are aware of and/or affiliated with the MS Society.

The questionnaires were launched on November 14, 2002, and were closed on January 15, 2003.

Respondents who requested a printed questionnaire were sent one by mail, with a pre-stamped return envelope. Other respondents completed questionnaires online through Society's web site. 109 people responded by mail and 259 responded online.

#### 3.2 Respondents

The questionnaire had 415 responses, of which 368 were completed (47 questionnaires submitted online were blank). 191 (52%) questionnaires were completed by a parent, 95 (26%) by an adult whose parent had MS, and 82 (22%) by a child.

Three-quarters of respondents who identified their gender were female and one-quarter were male.

Distribution by gender (of those who identified their gender):

All	73% female
Adult children	82% female
Children	58% female
Parents	75% female

Distribution by age (of those who identified their age):

Children:	Under 12 years	8%
	12 – 14 years	50%
	15 – 18 years	42%
Adult children:	18 to 25 years	44%
	26 to 35 years	30%
	36 to 45 years	20%
	Over 45 years	6%
Parents:	19 to 25 years	2%
	26 to 35 years	18%
	36 to 45 years	48%
	46 to 55 years	26%
	Over 55 years	6 %

Almost 80% of the children were under 6 years old when their parents were diagnosed with MS.

Responses came from across Canada, predominantly from Ontario, the West and Quebec.

Distribution by province:

Alberta	49	(13.3%)
British Columbia	68	(18.5%)
Manitoba	14	(3.8%)
New Brunswick	6	(1.6%)
Newfoundland	4	(1.2%)
Northwest Territories	0	(0%)
Nova Scotia	13	(3.5%)
Nunavut	0	(0%)
Ontario	101	(27.4%)
Prince Edward Island	0	(0%)
Quebec	46	(12.5%)
Saskatchewan	12	(3.3%)
Yukon	2	(0.5%)
Skipped this question	53	(14.4%)

Distribution by type of community (those who identified the type of community):

Large city (1 million or more)	19.1%
Small city (100,000 to 1 million)	34.0%
Town (under 100,000)	24.3%
Rural community	22.6%

The questionnaires also attempted to identify the type of MS in the respondents' family. The most common types of MS identified by respondents were:

Relapsing-remitting	33%
Secondary-progressive	15%
Primary-progressive	8%
Progressive-relapsing	5%
Did not know	18%
Did not answer	21%

### **3.3 Focus groups**

A series of five focus groups were conducted with children aged 6-12 to hear their views on the impact MS has on their lives.

Focus groups were held in January 2003 in Barrie, Hamilton and Ottawa, ON, and Montreal and Hull, PQ.

A total of 30 children participated in the focus groups with the following age distribution:

Age 6	3	(10%)
Age 7	5	(16.7%)
Age 8	3	(10%)
Age 9	5	(16.7%)
Age 10	6	(20%)
Age 11	2	(6.6%)
Age 12	6	(20%)

Of the total number of children, 13 (43.3%) were boys and 17 (56.7%) were girls.

To identify the focus groups participants, MS Society Chapter Client Services Managers contacted directly affiliated families with children and/or mailed out a call-for-volunteers flyer in their communities. The call for volunteers was also posted on the MS Society's web site. Due to a lack of volunteers two other focus groups in Toronto, ON, and Vancouver, BC, had to be cancelled.

To ensure consistency among the focus groups, facilitators were trained to use a set of guidelines designed for conducting the focus groups. (*Appendix 3*)

### 3.4 Interpreting opinions of children and adult children

Based on existing research on recollections of adult children who grew up with a parent with MS, the project team decided to include both children and adult children in the survey because we felt that there could be differences and that maturation could play a factor. This supposition was confirmed by the differences in opinion of questionnaire respondents as well as the focus groups.

However, the differences between children (18 and under) and adult offspring of people with MS are difficult to interpret because a number of different factors may be operating:

- *Self selection in both samples.* Adult children who chose to participate may be more likely to have had ongoing and unresolved difficulties with parental MS. Similarly, children who participated may tend to come from families that are more open in dealing with MS.
- *Maturation effects.* Adult children may have recognized later in life some of the challenges that they faced earlier in life but which were not fully recognized at the time or are left unstated in young children due to factors such as guilt.
- *System changes.* The experiences of adult children may reflect outmoded approaches and service deficits that no longer exist.

Because of these biases, adult children may tend to overstate the issues, while children may understate them. At the same time, the project team felt that adult children presented a perspective that should not be missed. The views of children and parents tend to be the same in almost all areas. It is adult children who can provide insight on what today's children may think and feel in 10 years. Therefore, the project team considered that the benefits of including the opinions of adult children outweighed the challenges of interpreting the results.

### 3.5 Definitions

In the following analysis and tables, a number of different groups are compared. These are the definitions of the terms:

- **All** – All the people who completed the questionnaire.
- **Parents** – Parents with MS and parents who do not have MS.
- **Children** – Children with a parent with MS.
- **Children aged 6-12** – Children currently aged 6-12 with a parent with MS.
- **Children aged 12-18** – Children currently aged 12-18 with a parent with MS.
- **Adult children** – Adults who as children had a parent with MS.
- **Strong family** – All respondents indicating that they agree or strongly agree with the statement “Overall, we are a strong family.”
- **Weaker family** – All respondents indicating that they disagree, strongly disagree or neither agree nor disagree with the statement “Overall, we are a strong family.”

## 4 Key findings

The purpose of this survey is to identify areas in the emotional, social, educational and physical well-being in which children of people with MS need support to grow up strong. This chapter highlights key findings that are described in greater detail in Chapters 5-11.

### 4.1 Impact of MS on children

The questionnaire data indicates that approximately 37% of children and adult children frequently find their parent's MS upsetting. Almost 50% of adult children report that their parent's MS has been upsetting "frequently" or "all the time." Almost 60% of children from weaker families report that their parent's MS has been upsetting "frequently" or "all the time."

The survey results consistently show powerful impacts on the emotional and social development of children. MS has the highest levels of impact on the children's emotional development, participation in recreational activities, behaviour, and social activities with friends. School performance and physical activities are affected to a much lesser extent.

In three groups – all respondents, children aged 12-18, and people from strong families – 30 to 40% believe that children are affected "quite a bit" or "a great deal" by their parent's mood changes and emotional outbursts. The same percentage of these groups worry about the parent's MS, the stresses it causes between the parents and not knowing what to expect. In all these areas, children indicate that they are affected more than the parents perceive them to be in their responses.

Children aged 12-18 say that the MS-related lifestyle limitations affect the entire family in all areas of life, especially having fun as a family. They also report limits on vacations and the normal social activities of the children, and, to a lesser extent, limits on recreational and sports activities.

Children aged 6-12 identify similar impacts of MS: parent's need to rest, limitations on activities, and changes in parent's involvement in their life.

Adult children consistently report a higher negative impact on themselves than expressed by children or by parents. The exact reasons for this are not clear. Similarly, when the views of strong and weaker families are compared, weaker families consistently report more negative impacts of MS.

### 4.2 Children providing support at home

Based on their self evaluation in the questionnaire, respondents tend to see children as having substantially more responsibility than children in homes where a parent does not have MS, in activities such as: laundry, meal preparation, baby-sitting, personal care for the person with MS, medical care for the person with MS, and managing the house.

However, when answering open-ended questions – referred to as “qualitative results” – most parents indicate that the expectations on their children are pretty normal. Only a small portion (less than 10% of parents who responded to this question) say that responsibilities are heavier than other children for household activities such as cleaning and cooking.

Most children (80-90%) are reported as being happy with their household and family tasks. The highest levels of unhappiness among the children are related to household tasks (laundry and cleaning, etc.), personal care and medical care of the person with MS, in which 14% to 17% are unhappy.

The reported levels of unhappiness in the weaker families range between 30% and 35%, substantially higher than in strong families.

### **4.3 Strategies to cope with the impacts of MS**

Ninety-four percent of the respondents indicate that it is quite important or very important for children to understand MS. This is a strong and recurrent theme in the focus groups, whose participants were children aged 6-12. Even the youngest children want to have opportunities to talk and ask questions. Most children have been told about MS by their parent. Children also want to be involved in helping their parent. They want to gain some control over MS by knowing what to expect, particularly whether a person could die from MS. Children also want other people – those directly involved in their lives as well as the general public – to be better educated about MS.

However, many of the families do not employ strategies that could be effective in reducing the emotional impacts and fears that children have about MS or in reducing the impacts in other areas of their lives. For example, 40% of children aged 12-18 indicate that they do not talk about emotions and fears that result from a parent’s MS.

Here, the differences between strong families and weaker families are significant; weaker families are much less likely to develop strategies to deal with the impacts of MS.

### **4.4 Children learning to deal with their feelings about their parents’ MS**

Children learn how to deal with their feelings first and foremost from family members. Children aged 12-18 from strong families more frequently identify parents, brothers and sisters, and other family members, as well as MS Society materials, as the primary sources of information. Children from weaker families identify friends as sources more frequently than children from strong families. Health professionals are more frequently identified by people from weaker families.

Overall, approximately 35% of adult children and 23% of children aged 12-18 indicate that they did not learn to cope with their parent’s MS. When children from strong and weaker families are compared, it is clear that a higher proportion of children from weaker families have not learned how to deal with their feelings.

#### **4.5 Information needs regarding MS**

Over 90% of those surveyed indicate that it is quite important or very important that children understand this illness. Just over half say the children understand the disease quite a bit or a great deal.

The top two areas where parents and children need information relate most significantly to emotional and social interactions related to MS. While facts are needed, addressing the emotions and fears associated with MS and strengthening the coping skills of the children are regarded as being even more important. The parents are also seen as needing parenting tips for families with MS. Similarly, children need information on how to talk to their parents as well as their friends. These often tie into the emotional and social interaction needs of the children of people with MS.

Most children learned about MS from parents (83%) and printed materials or videos from the MS Society (40%). Asked about their ability to find materials about MS for different age groups, respondents indicate that most of the information available is aimed at teenagers; there is much less material for younger children.

Respondents feel the best way to get information is through videos, followed by the Internet, written materials and school programs, more than meetings.

#### **4.6 Program needs**

The most frequently identified needed programs do not deal directly with MS itself. The top priority for all respondents is the need for programs that strengthen understanding in schools and communities about challenges that children face when a parent has a health problem or disability. The top priority for weaker families and second priority for the other groups focus on skills for creating strong families. The top priority for adult children is programs for children to learn about MS. Following these top priorities are programs specifically geared to activities and support for children and families with MS. Some relate to information, others to support. Pulling extended family together to have fun and provide caregiving support is identified twice as frequently as teaching the extended family about MS.

Opinions on the best vehicles for providing such programs are consistent with those identified for information needs, with videos and written materials cited as the best approaches.

## 5 General findings

### 5.1 Family strength-related findings

The questionnaires asked a number of questions, listed below, that are indicators of strong families. At the end of this section, it asked whether they agreed or disagreed with the statement “Overall we are a strong family.” Three-quarters (76%) either strongly agreed (43%) or agreed (33%), while one-quarter neither agreed nor disagreed (15%), disagreed (6%) or strongly disagreed (3%).

When the responses to this section of the questionnaire are compared, there are many substantial (and statistically significant) differences in the views expressed by people from strong families and from weaker families. Members of weaker families are substantially less likely to agree or strongly agree with any of the statements. In many cases, the differences are statistically significant.

The following table highlights the proportion of strong families that “strongly agree” or “agree” with a given statement compared to weaker families. The differences are statistically significant at .05 unless marked (ns).

<b>Strength of Family - % who “agree” or “strongly agree” Statement given</b>	<b>All families</b>	<b>Weaker families</b>	<b>Strong families</b>
Enjoy helping each other	75	42	86
Like to shared feelings	55	20 (ns)	66
Feel responsibilities are shared fairly	53	18 (ns)	64
Have a positive attitude to life	74	39	84
Work together to solve difficult family problems	66	19	81
Give each other a chance to do new things	74	43	83
Like to show affection	72	32	84
Everyone gets a say in decision making	53	14	65
Enjoy learning about family history	62	42	69
Crisis helps make our relationships strong	59	18	72
We like to talk openly with each other	57	43 (ns)	70
We have reasonable expectations of each other	63	15	78
Positive relations with extended family	69	55 (ns)	73
Able to face daily issues confidently	66	30	78
Have lots of good times together	77	35	91
Respect the roles that each plays in the family	67	22	82
There is a feeling of safety and security	73	38	85
Believe love is a powerful force that keeps us together	78	38	92
Sarcasm is not generally used	39	22 (ns)	43
We wait for each other without complaining	40	8	50
Life in our family is satisfying to us	67	17	84
We have enough time for each other and enjoy time together	65	17	80
We are happy as a family	75	21	92
We value each other and are committed to our well-being as a family	81	36	95
We look at challenges as opportunities for growth	59	14	73
Overall we are a strong family	76	0	100

As part of the data analysis, the total scores of each person’s responses to the 25 questions were also added together and correlated to their answer to the statement “We are a strong family.” There is an 89% correlation between the total score and the answer to the statement, indicating strong agreement. We can conclude, therefore, that respondents’ assessment of the strength of their families is quite accurate.

## 5.2 Type of MS and its relationship to family strength

A review of the data indicates that:

- 79% of families with relapsing-remitting MS indicate that they are strong families.
- 72% of families with secondary-progressive MS indicate that they are strong families.
- 71% of families with primary-progressive MS indicate that they are strong families.
- 65% of families with progressive-relapsing MS indicate that they are strong families.
- 75% of families that did not know the type of MS indicate that they are strong families.

The number of people completing the questionnaires is not large enough to statistically identify a relationship between the type of MS and family strength.

## 5.3 “Strong families” and “weaker families” are different

Strong families are much more likely than weaker families to report that MS has had a positive effect on their children over a range of emotional, social, recreation and educational factors. The differences are most pronounced in the relationship between parents and children, the behaviour and the emotional development of the children.

	Strong families % very positive or positive impact	Weaker families % very positive or positive impact	Strong families % positive or no impact	Weaker families % positive or no impact
Participation in recreation activities	24	8	81	61
Friendships with people their own age	30	16	93	78
Social activities with friends	26	13	86	67
Emotional development	48	22	83	57
Behaviour	44	15	88	51
Relationships with parent	61	31	90	56*
School performance	27	12	86	70
Physical health	28	11	87	74

(\*) - Statistically significant difference.

### Levels of happiness

Children from strong families also indicate higher levels of happiness related to activities in the home when compared to children from weaker families. The differences between stronger and weaker families are substantial in all areas, with the exception of babysitting.

<b>Children are happy to help at home with:</b>	<b>Strong families % “very happy” or “happy”</b>	<b>Weaker families % “very happy” or “happy”</b>	<b>Strong families % “happy” or “neither happy nor unhappy”</b>	<b>Weaker families % “happy” or “neither happy nor unhappy”</b>
Household tasks	43	21	88	68
Meal preparation	54	32	93	70
Babysitting	37	25	94	83
Personal care for parent	35	21	90	65
Medical care for parent	31	22	94	66
Managing house	23	19	94	72
Independently caring for self	56	29	92	73

## 6 Impact of MS on children

### 6.1 Negative impacts

The questionnaire asked a number of questions about the impacts of MS and its symptoms on the children in the household. When children and adult children are asked the overall question “Has your parent’s MS been upsetting to you?”

- 37% indicate that the parent’s MS was upsetting “quite often” (27%) or “all the time” (10%).
- 46% of adult children indicate that the parent’s MS was upsetting “quite often” (33%) or “all the time” (13%).
- 16% of children aged 12-18 indicate that the parent’s MS was upsetting “quite often” (12%) or “all the time” (4%).
- 58% of questionnaires from weaker families indicate that the parent’s MS was upsetting “quite often” (33%) or “all the time” (25%).

When parents and children are asked about the impact of MS on different aspects of life, the results vary. The impact may have been positive or negative or there may have been no impact at all. The table below shows the percentage of the questionnaires that indicate a negative impact.

Percentage reporting a negative impact on children’s:	All families	Children 12-18	Adult children	Strong families	Weaker families
Participation in recreation	19	16	18	14	32
Friendships	8	4	12	4	18
Social activities with friends	16	16	20	11	30
Emotional development	20	13	33	14	38
Behaviour	18	11	24	10	41
Relationship with parent	15	11	24	6	40*
School performance	14	7	17	10	26
Physical health	12	8	19	10	20
Other	16	8	25	12	31

This table illustrates that 15 to 20% of the respondents report a negative impact on children in these specific areas. Participation in recreational activities, emotional development, behaviour, social activities with friends, and relationship with parents show the highest negative impacts.

When the views of children are compared, adult children indicate that the impact is more negative than children aged 12-18, especially related to emotional development, behaviour, and relationships with parents. None of the differences are statistically significant, however. The project team also compared the views of parents and children but have not included this in the table above, as they are almost identical, with no statistically significant differences.

When strong and weaker families are compared, the weaker families report negative impacts two to three times higher than strong families. Approximately 40% of weaker families report that there is a negative impact on the children as a result of MS related to emotional development, behaviour, and relationship with parents. One-quarter to one-third of these families report a negative impact on participation in recreational activities as well as social activities with friends. Only the difference in impact on the relationship with parents is statistically significant (\*).

### 6.1.1 Qualitative information

The analysis of the open-ended responses to the questionnaire indicates that a parent's MS has negative impacts on:

- **Emotional development of the children** – acceptance of the disease, fear of the future, worry, depression.

*“I think that we are more responsible when a family member had MS. My Mom has MS and she is an awesome person. She has helped me a lot in life but I worry about her that someday she may not walk. That I think is the hardest thing to accept. I feel very responsible for my Mom.”*

*“No sense of security [for the] future. Lots of fear.”*

*“I feel that my children's outlook in life in general is very negative. They go to school in fear that I will be in the hospital when they come home from school or that maybe I will die while they are in school. We have reassured them that people with MS do not die of MS. My middle child is really affected in a way that she is very withdrawn. She has become so emotional, crying at nothing... “*

*“[My] Middle son has panic attacks when I am admitted to the hospital due to a MS attack.”*

- **Relationships with parents** due to grumpiness, mood swings, bad temper.

*“I used to cry every single day because my dad and I would argue and because I felt to sad for my mother.”*

*“At times the symptoms of MS have caused negative behaviour by the adult with the disease. He is more likely to display a short temper and become frustrated with his inability to assist the children physically.”*

- **Children's responsibilities** – for household tasks, etc., loss of ability to do things as a family or with friends.

*“When other kids were outside playing, I was cooking dinner and cleaning the house. I don't think I had much of a childhood.”*

*“I think it made me grow up too fast. I became a little adult who tried to take care of everybody and never took care of myself.”*

*“... MS ... has made her feel left out from joining soccer or other sports [which] she would love”*

- **Social development** – lack of role model, parents don't entertain, fear of being judged, stresses between parents, loss of relationship.

*“ [My brother] was lacking a male role model for the most part as my father was struggling to cope with his MS.”*

*“MS had a negative effect on our family's social life. Mom and Dad didn't entertain much or have many friends over. Dad [with MS] didn't seem to have any close friends.”*

*“[My] daughter tried being Mother for a time until I got upset and told her that until I asked I was still capable of being her Mom and she was to be the daughter she always was”*

*“I think certain children do not dare to speak with their friends about their mother's disease because they are being afraid of being judged. They behave as if everything is normal, however they worry more than we can see.”*

- **Family resources** – lack of money to do normal things.  
*“Not having a salary and the ability to ... plan vacations adds extra stress on everyone.”*  
*“On a small disability pension, I have no funds left to pay for extra activities and can no longer go hiking with [my daughter] as we did frequently when I did not have this MS.”*

### 6.1.2 Focus group findings

The focus groups identify a number of similar themes:

- **Parents need to rest a lot.** The theme of “resting” is dominant in both the comments and pictures drawn by the children aged 6-12. The need for rest seems to be central to how life in the family is organized and the child’s involvement with the parent as well as outside activities. Children seem to understand parents’ need for rest and want to cooperate, but at the same time feel slightly resentful and suggest that their parents don’t fully appreciate the impact that this has on the children’s lives.
- **Limits on activities.** A number of children describe limitations in their independent activities that result from their parents’ MS. Again, often these are tied to the parents’ fatigue.
  - “You can’t run around as much as you did before.”*
  - “You can’t always have friends over because Mom/Dad is too tired”*
  - “ Have to stay in sometimes because Dad/Mom is too tired”*
  - “Can still play with children but not as much and in a different way, e.g. can’t play sports but can play board games like Monopoly and chess”*
  - “Friends may come over but they can’t stay because Mom is too tired.”*
  - “Can’t go to friends’ houses at night because my mom can’t pick me up if Dad is working because she can’t drive at night.”*
  - “I can’t join teams because one parent has to work and the other one has MS and can’t help out.”*
  - “Hard to socialize because she can’t pick me up after an event if she is too tired.”*

- **Changes in the parents' activities/abilities.** The children try to understand the changes that MS caused in their parents' abilities. Although they do not generally talk about a parent's decline, many made some reference to the fear that their parent would die of MS.

*"If you have MS you can't do as much as other people."*

*"You can't be outside standing too long because you get tired."*

*"Parent usually gets tired day after she does something."*

- **Parents' involvement in children's lives.** The children describe the changes in their parents' involvement in their lives as both positive and negative, and their feelings about these changes are mixed. They also talk about the variability in their parents' abilities.

*"They can't take you to the mall because they get too tired."*

*"If she wants to ski with her children she cannot because she would get exhausted too quickly."*

*"My mom can't walk me to school. My friend's mom does."*

## 6.2 Other impacts

In addition to the above, the questionnaires asked about a number of specific impacts on children. The results indicate that the children are affected as a result of a range of MS-related factors. The following table illustrates the percentage of respondents that indicate that children are affected "quite a bit" or "a great deal."

It also highlights the different perceptions of the people who responded. Parents have different perspectives than children, adult children have different views than children aged 12-18, and strong families have different views than weaker families:

- In all areas except embarrassment about symptoms, children indicate that they are affected more than the parents perceive them to be in their responses. (Significant differences are noted with > in the table below.) Moreover, when adult children of people with MS are asked about the same impacts, they often see them as even greater than the children aged 12-18 do. (Such differences are noted with \*.)
- People who identified themselves as being in a "strong family" have different views than people from weaker families (the differences are noted with Γ). Generally, people from weaker families indicate a greater negative impact than people from strong families.

To what extent does MS in your family result in: % “quite a bit” or “a great deal”	All	Children 12-18	Adult children	Strong families	Weaker families
Mood changes and emotional outbursts that affect the children	40	31	49	30	62
Limiting ability to do homework	7 >	9	9 *	2	20 Γ
Children not knowing what to expect	30 >	31	52 *	25	49
Stresses between parents that affect the children	35 >	34	50 *	23	69
Embarrassment about symptoms that affect children	16	13	22	11	30 Γ
Symptoms that make it difficult to hug or show affection	10	9	14	5	24 Γ
Fear by children that they will get MS or pass it to their children	22 >	22	40 *	18	34
Anxiety that when children get home from school parent will have gone to the hospital	27 >	37	50 *	25	30
Worry that when children get home from school parent will have become much sicker	38 >	38	76 *	35	49
Limiting the ability of children to participate in extra-curricular activities	17	16	23	12	31 Γ
Limiting the ability of children to do normal things with their friends	12 >	12	25 *	9	32 Γ

Significant differences:

- > - Indicates significant difference between parents’ and children’s views
- \* - Indicates significant difference between children aged 12-18 and adult children
- Γ - Indicates significant difference between strong families and weaker families

### 6.2.1 Specific findings of note

#### **Mood changes and emotional outbursts.**

40% (128) of responses from those who answered indicate that mood changes and emotional outbursts affect children. The impact is the highest in adult children and weaker families, but the differences are not statistically significant.

#### **Worry that when children get home from school parent will have become much sicker.**

38% (115) of responses from those who answered indicate that children are affected by worry that when they get home from school the parent with MS will have become much sicker. Adult children are twice as likely to say that they were affected quite a bit or a great deal. These differences are statistically significant.

#### **Stresses between parents that affect the children.**

35% (109) of responses from those who answered indicate that children are affected by stresses between parents. The impact is higher (50%) and statistically significant in adult children.

**Children not knowing what to expect.**

30% (95) of responses from those who answered indicate that children are affected by not knowing what to expect. The impact is higher (52%) and statistically significant in adult children.

**Anxiety that when children get home from school parent will have gone to the hospital.**

27% (83) of responses from those who answered indicate that children are affected by anxiety that when they get home from school a parent will have gone to the hospital. The impact is higher (50%) and statistically significant in adult children.

**Fear of children that they will get MS or pass it to their children.**

22% (69) of responses from those who answered indicate that children are affected by fear that they will get MS or pass it to their children. The impact is higher (40%) and statistically significant in adult children.

**Limiting the ability of children to participate in extra-curricular activities.**

17% (54) of responses from those who answered indicate that MS limits the ability of children to participate in extra-curricular activities. The impact is higher (31%) and statistically significant in weaker families.

**Embarrassment about symptoms that affect children.**

16% (52) of responses from those who answered indicate that the children are affected by embarrassment about MS symptoms. The impact is higher (30%) and statistically significant in weaker families.

**Limiting the ability of children to do normal things with their friends.**

12% (45) of responses from those who answered indicate that MS limits the children's ability to do normal things with their friends. The impact is higher and statistically significant in adult children (25%) and in weaker families (32%).

**Symptoms that make it difficult to hug or show affection.**

10% (31) of responses from those who answered indicate that children are affected by symptoms that make it difficult to hug or show affection. The impact is higher (24%) and statistically significant in weaker families.

**Limiting ability to do homework.**

7% (25) of responses from those who answered indicate that MS limits the children's ability to do their homework. The impact is higher and statistically significant in adult children (9%) and in weaker families (20%).

## 6.2.2 Qualitative information

Children of people with MS identified:

- **Lifestyle limitations.** Lifestyle limitations affect the children, the parent with MS, and the parent without MS. The limitations relate to all areas of life but having fun as a family comes up often, while limits on normal social activities of the children and vacations are also often mentioned. Limits on recreational and sports activities come up less frequently, but are a theme.

*“One of the things that is really difficult for me is the fact that my family can’t just go out to a park or something and have fun playing or whatever because I always see other families out doing that but my family has never been able to. Another thing that is difficult with my parents having MS [is that] everything takes a lot longer, like we have to walk slower and just little things like that.”*

- **Suffering.** Physical pain, emotional losses related to lifestyle changes, and other kinds of pain are felt not just by the person with MS but by all family members. One adult child described the *“emotional pain in seeing the daily struggles.”* Others wrote that *“Watching them deteriorate is painful.”*

- **Moodiness, grumpiness and how these play out in the family.** This is a strong theme. Living with a parent with MS can be like *“walking on pins and needles, not knowing what to expect each day,”* said one respondent. A couple of people talked about the person with MS inflicting their pain on the children on bad days.

*“The anger is by far[the] number one [challenge] in my life. I understand where it was coming from more now that I am an adult, and I was lucky enough to have known Dad when he was physically active. My younger siblings just know him as a bitter old man.”*

*“One of the most difficult things about having a parent with MS was that my mother lived in fear which was transformed into anger! My early childhood through my teens and early 20s [was] filled with arguments.”*

- **Loss of emotional support from the parents.**

*“Time is filled with caregiving. [You] feel abandoned by both parents.”*

*“Raising your parents is hurtful and hard.”*

*“As you get older I think you realize, or at least I do, that you never had the same sort of bond with your parent that other kids did. In some levels it was much deeper but in others it was missing all together.”*

- **Uncertainty.** How will a parent be today, how will he or she be in the future?

*“Thinking to the future: will my dad be there at graduation to walk me down the aisle, to see his grandchildren, etc. (I know it is selfish but it sometimes brought me to tears just thinking.)”*

*“The most difficult thing about having a parent with MS is the uncertainty that goes with the disease. When my mom wakes up in the morning we never know if she will be having a good day and will be able to function normally or if she will be having a bad day.”*

*“Everything was always changing. What worked one day didn’t work the next day.”*

- **Worry.** One of the fears expressed by children is that they will get the disease.

*“Being scared that you will grow up and be in pain too.”*

*“The unknown...wondering if I will develop it...not knowing how to help....”*

- **Anger, guilt**

*“From the first walker to now in a nursing home – the level of care to my mother from me is overwhelming. I feel I will not start to live until she has passed. I love her dearly and will not see her suffer – but this is costing two lives.”*

Parents talk about:

- **Lifestyle limitations from their own perspective.** Parents also regret the things they cannot participate in, such as vacations, school activities, family activities, sports, and fun.

*“My inability to participate in various physical activities with them [is the greatest challenge]. Even going on vacation with them is now pretty much impossible. We all miss this.”*

*“Trying to keep her outside with friends or doing fun stuff like bike riding and me power walking with her. I can't do all that exercise stuff [anymore] – like I used to go to the school and shoot hoops.... This is so hard. We use to do these things together but my legs will not allow it.”*

- **Lack of resources.** Lack of income, money, transportation, etc., reduces opportunities and activities.

*“Finance has been a big issue. Not having the second income really makes things difficult. The parent with MS is also the only licensed driver so outings have come to nearly a complete stop. Without money or transportation we feel very [cut off]. Being in a small town with NO public transportation and very little resources increases this [cut-off] feeling immensely.”*

- **Uncertainty**

*“Not knowing if I will be able to get up in the morning and be able to walk and do the things [I did] the day before.”*

*“Fear of the unknown. When is the next attack? How long this time? What about work – will they take him back this time?”*

- **Moods and how these affect relations with children.** One person said that the parent with MS has a nasty temper and uses it constantly against the children. Others said:

*“My erratic mood swings throughout the day. The kids don't know where I'm coming from sometimes. That's when I have to stop what I'm doing and think first before I say another word to them.”*

- **Deterioration and loss of autonomy**

*“[The greatest challenge was] suffering from an attack and losing the use of the whole right side of my body.”*

### **6.2.3 Focus group findings**

The focus groups also identify some of these themes. Many of the children indicate that they feel affected by the mood changes of their parent – often described as “grumpiness” due to being tired. They seem to feel responsible for the parent’s mood and try to change their own behaviour in order not to irritate the parent. A similar theme of “the difficulty because of the unpredictability” of the mood is also evident.

A number of children speak of tensions between their parents that they believe are related to MS.

## **6.3 Conclusion**

The questionnaire results consistently show strong impacts on children of people with MS in the areas of emotional and social development. School performance and physical activities are affected to a much lesser extent.

- 37% or over one-third of the children 18 years of age and younger indicate that MS is upsetting quite frequently or all the time.
- 46% or almost half of adult children of people with MS report that their parents’ MS has been upsetting frequently or all the time.
- Almost 60% of children from weaker families report that their parents’ MS has been upsetting frequently or all the time.

The more specific results suggest that 30 to 40% of all respondents, children aged 12-18, and people from strong families believe that children are affected quite a bit or a great deal by their parents’ mood changes and emotional outbursts, and worry about their parents’ MS, stresses between their parents, and not knowing what to expect.

The overall responses indicate that the MS has the greatest impact on:

- Emotional development (20%)
- Participation in recreational activities (19%)
- Behaviour (18%)
- Social activities with friends (16%)

When these results are broken down, different groups highlight impacts in different areas:

- Children report the highest levels of impact on participation in recreational and social activities with friends.
- Adult children report the highest levels of impact on emotional development, behaviour, and relationship with their parent, followed by participation in recreational activities, physical health, participation in social activities with friends, and school performance.
- Respondents from weaker families report highest levels of impact in largely the same order as those reported by adult children, but indicate much higher levels of negative impacts.

When the views of parents, adult children and children aged 12-18 on negative impacts of MS are compared, adult children consistently report a higher negative impact on themselves than expressed by children or by parents. The exact reasons for this are not clear. Similarly, when the views of strong and weaker families are compared, weaker families consistently report more negative impacts of MS.

## 7 Children providing support at home

The questionnaires indicate that most children help with a range of household and personal care activities in the home. These include activities such as laundry, meal preparation, baby-sitting, personal care for the person with MS, medical care for the person with MS, and managing the house. The extent to which they are expected to help varies. In household tasks and meal preparation 80 to 92% of the children are expected to help somewhat or a lot. In personal and medical care approximately 22 to 26% of children provide this care sometimes or a lot.

In all these areas, based on the evaluation of each category of respondents, children are seen to have substantially more responsibility than children in homes where a parent does not have MS. However, parents tend to see the children as having comparatively lower responsibility than the children believe they have. These differences are statistically significant in all areas except babysitting.

When adult children are compared to children aged 12-18, adult children report higher levels of responsibility in all areas. The differences are significant in all areas except household tasks.

In weaker families, children's participation in meal preparation and managing the house is slightly higher than in all families, while for personal care and medical care expectations are 37% and 38% respectively, 50% higher than in all families. None of these differences are statistically significant.

### 7.1 Qualitative information

The questionnaires asked an open-ended question about levels of responsibility. The answers to the question contradict the results of the quantitative responses. The reasons for the contradictory perspectives are unclear, but may be related to the fact that not all respondents chose to answer the open-ended question. The children aged 12-18 describe little outside the normal range of making their beds, doing dishes and general help around the house. Most of the adult children say the expected level of help around the house was similar to the expectations placed on other children. Household activities include general outside maintenance and work (gardening, mowing the lawn, etc.), as well as inside activities (cleaning, cooking, shopping, etc.). Driving to appointments and shopping is quite frequently mentioned. Babysitting is identified by a few. A small number indicate that there is a heavy responsibility on them, with the expectation that they will do everything. One respondent indicates that this was because the parent who does not have MS really did nothing. Another indicates the need to start working at age 11 to help support the family.

Most parents who responded to this question indicate that the expectations on their children are pretty normal. A small portion (less than 10%) say that responsibilities for household activities such as cleaning and cooking are heavier than for other children. An additional small group say physical help is provided by the children for lifting the person with MS if he or she fell.

## 7.2 Focus group findings

Many of the children express the perception that they are required to help out more or at least do different kinds of things than their friends who do not have a parent with MS. Some, however, feel their responsibilities are no different from their friends, particularly friends who have parents who work outside the home.

## 7.3 Level of happiness

When parents and children were asked how happy children are about their level of responsibility, most children (80-90%) are considered either “happy” or “neither happy nor unhappy.” The highest levels of unhappiness are related to household tasks (laundry, cleaning, etc.), personal care, and medical care, in which 14% to 17% are unhappy. There are no substantial differences between adult children and children aged 12-18.

<b>Children’s level of happiness % “unhappy” or “very unhappy”</b>	<b>All</b>	<b>Children 12-18</b>	<b>Adult children</b>	<b>Strong families</b>	<b>Weaker families</b>
Household tasks	17	13*	17	12	32
Meal preparation	13	8	16	8	30*
Babysitting	5	10	7	6	17
Personal care for parent	17	13	22	10	35*
Medical care for parent	14	11	19	5	35*
Managing house	5	10	14	6	28
Caring for self	13	9	20	8	27

In the weaker families, the reported level of unhappiness is much higher in all areas. Levels of unhappiness with household tasks, meal preparation, personal care, and medical care are all in the 30% to 35% range, substantially higher than in strong families (and most are statistically significant).

## 8 Strategies to cope with impacts of MS

Ninety-four percent of the respondents (301 of the 325 people who answered this question) indicate that it is quite important or very important for children to understand MS. In the focus groups with the younger children this is a strong and pervasive theme. Children want to understand and be involved in helping their parent. They want to gain some control over MS by knowing what to expect. Likewise, they want to know whether a person could die from MS. Children also want other people – those directly involved in their lives as well as the general public – to be better educated about MS. Most children have been told about MS by their parent. They want to have opportunities to talk and ask questions, even from a young age.

In the questionnaires people were asked about strategies that their family uses to cope with the impacts of MS, using three options: “no” (they don’t use this approach); “occasionally” (they use this approach); or “frequently” (they use this approach). Following are the percentages that said “no” (significant - \* / not significant - ns).

Strategies that their family use to cope with the impacts of MS: <i>% indicating “no”</i>	All families	Children 12-18	Adult children	Strong families	Weaker families
We talk about the emotions and fears that result from a parent's MS	30 *	40	44 *	26	40 ns
We talk openly about the symptoms of MS so that children can understand the disease	20	26	16	16	32 ns
We have developed ways of showing affection when physical contact is difficult	19	25	31*	13	37 *
We work together so that MS doesn't affect homework	14 *	24	22 *	8	31 *
We work together so that MS doesn't affect sports and extracurricular activities	14	22	16	10	26 *
We have developed ways to support/ attend school activities	12 *	17	19	8	24 *
We talk openly about extra caregiving demands on family members	21	33	25	17	34 *

These results suggest that many of the families have not used the strategies that could be effective in reducing the emotional impacts on children. Among the adult children, 44% indicate that their families did not talk openly about their fears and emotions about MS, 31% had not developed ways of showing affection, and 22% had not developed ways of working together to deal with homework.

The differences between strong families and weaker families are also significant, with weaker families much less likely to develop strategies to address the impacts of MS.

The failure to develop these strategies could be contributing to unhappiness in other areas, such as the discontent with household chores mentioned in the previous section.

## 8.1 Qualitative information

The questionnaires asked what works best in their family to support children to grow up strong. Overwhelmingly, the most frequently identified things are talking and caring about the people in the family.

- For respondents, “**talking**” meant dealing with all issues, not just MS. Communication should be honest and respectful. Parents should include children in decisions while also letting them be children. Families needed to take a positive approach by making MS just “*a bump in the road,*” working together and leading a normal life.

*“I do think it is important for your parents to talk to you about it and have them tell you how they are feeling that day. That way you know if you are going to have to[do] extra work or if things will just stay the same.”*

*“Talk openly and frequently about MS and all aspects of the family life... educate... educate... educate!”*

*“The most important thing that any family can do to help their children deal with MS is to talk to them and answer any questions that they might have and to dispel any myths they have heard.”*

*“Give them booklets to help them understand and have discussions and talk over what MS is.”*

*“Talk with kids. Kids are scared when they don't understand what is going on. I think it would also be great to give kids a chance to find and talk with other kids going through the same thing. Just as there are support groups for people living with MS [and] the caretakers of those living with MS, there should be support groups or camps for kids of parents with MS. This would give kids a feeling of not being alone. I think there should also be more literature, especially about things that scare kids like the future health of their parents and the kids' own health future, available for kids. Kids dealing with issues like this have to be treated like kids (have fun with them). However they also need a serious side, as they are dealing with some[thing] far more mature than other kids their age have to deal with.”*

- **Caring about the people in the family** includes showing love and care for everyone in the family but also giving children special support. Respondents make suggestions such as: hug your children; show love and affection; provide emotional support; make the environment safe for children; encourage your children.

*“Make them feel special, too, and appreciate the help and sacrifices they give.”*

*“Explain to them that the parent isn't well but show unending love to the child(ren).”*

*“Give the children lots of affection, and strive to keep their lives uncluttered with worry by talking about MS often, and allowing the children to express their fears, and making sure that the children's schoolwork and activity level doesn't suffer.”*

*“We occasionally bring them to doctor's visits [and] support group meetings. Talk openly in language they understand when their mother's progression worsens. Let them*

*be more involved in her care when they are comfortable with it. Let them decorate (within limits) her mobility aids (a craft-time of sorts). We believe this gives them some sort of feeling of control. Try to live as normal a life as possible.”*

- **Make life fun** – joke, use humour, and laugh.

*“Keep laughing - humour is the most [important] element of getting through such challenges.”*

*“Humour has been the most effective way in my household. When your teens comment that perhaps you have only consumed a pint instead of a quart (meaning your walking is better) and they laugh WITH you that is a good thing.”*

Respondents also mentioned these factors:

- Help children to talk about feelings and emotions and get professional support when they need it.
- Create opportunities for children to participate in normal activities.
- Work together to make sure that parents can participate in school activities.
- Encourage children to talk to others in similar situations.
- Talk early about extra responsibilities.
- Be patient.
- Get support from family and community organizations to reduce fatigue.
- Build a support network.

The responses reflect many of the qualities that create strong families.

## **8.2 Focus group findings**

The focus groups also indicate that children aged 6-12 need and want to understand and adapt. A significant theme was that children desperately want to understand and support their parent. In order to do this, they feel they need information and skills in order to “*do what is needed.*” This is evident even among the youngest children in the groups.

## 9 Children learning to deal with their feelings about parental MS

The questionnaires asked the children as well as the parents how the children learned to deal with their feelings. A range of options was provided, and respondents were asked to indicate all that applied. Children were provided with an additional option “I didn’t learn,” which was not included on the parents’ questionnaire.

### 9.1 Children who didn’t learn to cope

The following table illustrates the percentage of children indicating that they did not learn to deal with their parents’ MS. Overall, approximately 35% of adult children and 23% of children aged 12-18 indicate that they did not learn. When children from strong and weaker families were examined, it is clear that a higher proportion of children from weaker families have not learned how to deal with their feelings.

<b>Percent of children of people with MS who said they didn’t learn how to deal with their feelings about their parents MS:</b>	<b>All</b>	<b>Weaker families</b>	<b>Strong families</b>
Adult children	35	50	29
Children aged 12-18	23	38	18

### 9.2 How children learned to deal with the parents’ MS

The overall results from the questionnaire indicate that children learn how to deal with their feelings first and foremost from family members. The person with MS is most frequently identified, followed by the other parent, other family members, and brothers and sisters. MS Society materials and friends are next important, but generally less so than family members.

The table below highlights some differences between strong and weaker families. In strong families a much higher proportion learn from parents than from other sources. In weaker families parents are still the most frequently identified source, but MS Society materials, friends, and health professionals are more prevalent.

<b>How children learn to deal with feelings about parental MS % of respondents identifying this approach</b>	<b>All respondents</b>	<b>Strong families</b>	<b>Weaker families</b>
Parent with MS	59	63	46
Parent without MS	41	46	32
Brothers & sisters	18	20	13
Other family members	23	25	19
Friends	16	15	19
Health professionals	11	9	15
Support groups	3	3	2
MS Society materials	22	21	25
MS Society staff and volunteers	4	5	2
Internet	5	9	11
Other	10	8	16

When parents, adult children, and children are looked at separately, there are a number of clear differences.

<b>How children learn to deal with feelings about parents' MS % of respondents identifying this approach</b>	<b>Parents</b>	<b>Parents from weaker families</b>	<b>Parents from strong families</b>	<b>Children aged 12-18</b>	<b>Children from weaker families</b>	<b>Children from strong families</b>	<b>Adult children</b>	<b>Adult children from weaker families</b>	<b>Adult children from strong families</b>
Parent with MS	78	77	78	41	38	43	37	4	50
Parent without MS	54	57	54	23	14	26	37	7	41
Brothers & sisters	19	22	18	11	5	13	23	4	31
Other family members	29	32	27	19	14	21	17	4	22
Friends	12	12	11	12	19	10	29	31	28
Health professionals	12	17	10	7	5	8	12	19	8
Support groups	4	5	3	2	0	3	2	0	3
MS Society materials	28	42	24	18	10	21	13	11	13
MS Society staff and volunteers	5	5	5	4	0	5	3	0	4
Internet	10	15	9	10	10	10	10	4	7
Other	4	10	2	11	14	10	20	27	18

These results indicate substantial differences between parents, adult children, and children. Parents more frequently indicate that children learned how to cope from the parents and there were few differences among strong and weaker families. Parents from weaker families more frequently identify outside sources such as health professionals, MS Society materials, and staff.

Children aged 12-18 from strong families somewhat more frequently identify parents, brothers and sisters, and other family members, as well as MS Society materials. Children from weaker families identify friends more frequently than children from strong families do.

Adult children from strong families identify parents, brothers and sisters, and other family members substantially more frequently than people from weaker families. Friends are frequently cited by both groups. But for adult children from weaker families, friends are the most frequently identified support group, whereas in strong families, friends are identified much less frequently than parents. Health professionals are more frequently identified by people from weaker families compared to strong families.

## 10 Information regarding MS

Over 90% of those questioned indicate that it is quite important or very important that children understand this type of illness. Among parents who answered the question, approximately 95% told their children about the parent's MS. Just over half said the children understood the disease quite a bit or a great deal. A further 30% indicate that the children know a bit about the disease.

Most children learned about MS from:

- Parents (83%)
- Printed materials and videos from the MS Society (40%)
- Internet (20%)
- A health professional (15%)
- MS Society staff & volunteers (9%)
- Attending an education session

Asked about their ability to find materials about MS for different age groups, responses indicate that information is mostly available for teenagers and much less for younger children.

- 57% found quite a bit or a great deal of materials for children aged 12-18
- 25% found quite a bit or a great deal of materials for children aged 6-11
- 10% found quite a bit or a great deal of materials for children aged 2-5

More importantly for this project:

- 80% found very few or no materials at all for children aged 2-5
- 40% found very few or no materials at all for children aged 6-11
- 16% found very few or no materials at all for children aged 12-18

### 10.1 Type of information needed

We asked all audiences for the top three types of information needed by parents. Following are the choices in order of greatest frequency:

- Talking to your children about MS (55%)
- How to help your children talk to you about MS (45%)
- Parenting tips for families with MS (38%)
- Information on MS therapies (37%)
- Facts about MS (36%)
- Information on MS symptoms (25%)
- How to support children providing personal and medical care (20%)

The results indicated little difference in opinion between parents and children, except that parents tend to want more information related to MS therapies specifically while the children indicate that parents need information on MS Facts.

We also asked for the top three types of information needed by children aged 6-12 and those aged 12-18. Following are the choices in order of their greatest frequency (there were no significant differences among families):

Information needs (%)	Children aged 6-12	Children aged 12-18
Expressing feelings	50	48
Coping strategies	34	37
MS facts	32	30
How to explain MS to friends	31	26
How to talk to parents	31	26
Taking on added responsibilities	29	35
MS symptoms	24	21
MS therapies	7	14
Personal/medical care of MS patients	7	13

The top priorities identified for both groups of children are almost identical. The only difference in order was for the older group, where all respondents identify “taking on added responsibilities” as more important than for younger children. When the views of parents, adult children and children aged 12-18 are looked at separately, the only substantial difference noted is that both groups of children rank the facts about MS much higher than parents ranked this.

It is worth noting that three of the top information needs of parents and four of the five top information needs of children concern the emotional and social needs of children of parents with MS.

In the qualitative responses, respondents indicate that education and information is needed by people with MS, their families, and the general public. Such information is needed in various forms, ranging from videos and games to newsletters. The information should take a positive approach, be age appropriate, be understandable and engaging. It also needs to address all of the various types of MS. It should be more accessible for people in rural communities and be kept up-to-date.

## 10.2 Best information channels

The questionnaire asks for the best three channels for delivering MS-related information. Following are the percentages of the respondents who indicate the various channels:

- Video 45%
- Internet 42%
- Written materials 40%
- School programs 35%
- Meetings 28%
- Games 25%
- CD-ROM 20%
- Audio 4%

There are few substantial differences between parents and children. Adult children rank written material higher than parents and children aged 12-18, who rank school programs most highly. Parents rank videos most highly. In spite of these differences, all groups chose the same top four methods.

The children in the focus groups had many ideas about the kinds of educational resources and opportunities that could be informative and helpful. Clearly, a variety of approaches is needed to match with the diverse learning styles and situations of children. The children were very engaged in discussing the potential content and format of resources and their desire to participate in the creation of such materials.

### **10.3 Conclusions**

The top two areas where parents and children need information relate most significantly to emotional and social interactions related to MS. While facts are needed, addressing the emotions and fears associated with MS and strengthening the coping skills of the children seem to be even more important. The parents are also seen as needing parenting tips for families with MS. Similarly, children need information on how to talk to their parents as well as their friends. These often tie into the emotional and social interaction needs of the children of people with MS.

The preferred channels for information are videos, the Internet, written materials and school programs, rather than meetings.

## 11 Programs identified as helpful

The questionnaire asks people to identify the three programs that they thought would be most helpful. Following are the programs most frequently identified, ranked in order of the percentage of all respondents that identified each program.

Programs (%)	All	Parents	Children 12-18	Adult children	Weaker families
Programs to help teachers, schools and organizations understand challenges some children face when parent has health problems or disabilities	43	51	24	44	36
Programs to help parents develop skills for creating strong families	36	38	28	41	42
Support groups for children	34	36	26	36	33
Recreation programs and camps for children of people with MS	31	31	28	33	32
Programs to pull families together so they can have fun together	24	20	26	30	29
Programs to help children learn about MS *	21	N/A	40	48	14
Programs to pull families together so they can provide caregiving support	21	15	23	29	31
Programs to teach extended family about MS	18	19	16	16	16
Meetings and support groups for parents in similar situations *	16	30	N/A	N/A	17

**\* Note**

There is very little difference in how the groups rank the programs and services – with a few notable exceptions. Questionnaires for some groups included choices that were not on the questionnaires used by other groups. Parents were offered the additional choice of “*meetings and support groups for parents,*” and children were offered “*programs for children to learn about MS.*” While parents ranked meetings and support groups fifth on their list, adult and younger children ranked programs for children to learn about MS as first on their lists.

### 11.1 Qualitative responses

The qualitative responses in the questionnaire indicate the need for:

**Support programs:** A wide range of support programs is identified including programs for children, parents, partners, and families. Children of people with MS tend to identify support programs for children, while parents tend to recommend supports for families.

The specific types of supports that children talk about include:

- Emotional support.
- Coping skills.
- Assuring the children they did not cause the disease.
- Teaching children how to talk to parents.

Parents talk about the things that make families strong:

- Communication.
- Strategies to help raise strong children.
- Parenting tips.
- Developing support networks.
- How to get families working together.

Many people talk about the importance of providing a positive, fun approach using humour.

The programs discussed include:

- Support groups.
- Individual counselling.
- School counselling.
- Mentoring programs like Big Brothers.

**School programs:** Respondents believe school programs could:

- Improve students' knowledge of MS.
- Increase understanding of the MS impact on their friends.
- Engage students in helping friends whose parents have MS.
- Increase teachers' understanding and support for students with parents with MS.

Some respondents encourage program developers to broaden the discussion from just MS to disabilities in general.

**Activities and camps:** A few respondents identify activities and camps as an important way of allowing children to be children. One talks about the importance of programs to enable children to do things they would normally do with a parent, if the parent didn't have MS. It would be crucial to make such programs financially accessible.

**Services and resources:** Children as well as parents identify the need for additional in-home support for physical care of the person with MS and household activities (cleaning, cooking, etc.).

**Financial resources:** A small number of respondents indicate that there is a critical need to reduce the financial impact of MS, which can result in poverty and limited access to transportation, especially for single parents and people living in rural communities.

## 11.2 Best channels identified for providing programs

The questionnaire asks for the best mechanisms for delivering the above-mentioned programs. Following are the percentages of the respondents who indicate each method:

- Videos 47%
- Written materials 41%
- Meetings 41%
- School programs 37%
- Internet 35%
- Games 16%
- CD-ROM 15%
- Audio 5%

## 11.3 Conclusions

All the different groups rank the needs for programs in generally the same order with a few exceptions. The top choices are programs that deal with emotional and social issues, rather than MS itself. The top priority for all respondents is the need for programs that strengthen understanding in schools and communities about challenges that children face when a parent has a health problem or disability. The top priority for weaker families and second priority for the other groups is teaching skills for creating strong families. The top priority for adult children is programs for children to learn about MS. Following these top priorities are programs specifically geared to activities and support for children and families with MS. Some groups put more emphasis on information, some on support. One area of note is that pulling extended family together to have fun and provide caregiving support is identified twice as frequently as teaching the extended family about MS.

The respondents' preferred methods for providing these programs are similar to their preferred methods for the delivery of information, with videos and written materials as the best approaches.

## 12 Appendix 1

**Studies related to early years development, children of deaf people, people with mental health challenges, and arthritis highlighted needs similar to the needs of children of people with MS.**

*Survey for Teens of Deaf Parents*, (not dated), Through the Looking Glass Research Center, California.

B.E. Compas, S. Ey, D. Howell, and N. Worsham: *When Mom or Dad Has Cancer: II. Coping, Cognitive Appraisals, and Psychological Distress in Children of Cancer Patients*, *Health Psychology* (1996); 15 (3): 167-175.

Joanne Nicholson et al.: *Critical Issues for Parents with Mental Illness and their Families* (2001), Center for Mental Health Research Services Research, University of Massachusetts.

*Supporting Children and Young People in Families where a parent is living with a Mental Health Problem* (2001), Queensland State Network, Australia.

Pauline Banks, Eamonn Gallagher, Malcolm Hill and Sheila Riddell: *Young Carers: Assessment and Services Literature review of identification, needs assessment and service provision for young carers and their families* (2002), University of Glasgow.

John Defrain: *Strong Families* (1999), Family Matters No. 53, Winter.

*Children with parents with a disability*, Australian Social Trends 2000 - Family Formation: (2000) Austats.

## **13 Appendix 2**

**Questionnaires for children aged 12-18, adult children and parents and partners used as tools for the survey.**



Multiple Sclerosis  
Society of Canada

## **GROWING UP STRONG SURVEY**

### **Questionnaire for CHILDREN (age 12-18) of parents with multiple sclerosis**

*Hello!*

*Thank you for taking the time to help us.*

*Before you start, we want you to know that the personal information you give us in this survey will be kept private. No names will be used in any presentation of the information that is collected. We won't even ask for your name!*

*The MS Society of Canada is conducting this very important survey to gather information about how parents with multiple sclerosis (MS) and their families support the emotional, social, educational, and physical development of their children. This information will be used to identify areas where additional programs or support from the MS Society could be helpful.*

*We know that all families are different, but each family has many strengths. We would like your help in understanding how your family works, whether MS has presented challenges to your family, and how your family has tried to overcome these challenges.*

*We will also ask for your ideas about how the MS Society of Canada could support families so that they can be as strong as possible and enable their children to "Grow Up Strong."*

*There are no right or wrong answers to the 35 questions in this survey. Please answer according to how you think or feel about each question. We want to learn as much as we can from you.*

*Thank you so much for your participation!*

*We would like to know about your family and how it works. Please check (✓) the box that best matches your family situation. If the statement doesn't apply to you and your family situation, please leave it blank and go on to the next one.*

**1. In our family ...**

	Agree strongly	Agree	Agree somewhat	Disagree somewhat	Disagree
We enjoy helping each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We like to share our feelings with each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Responsibilities are shared in a fair way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have a positive attitude toward life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We can work together to solve very difficult family problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We like to give each other a chance to do new things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We like to show affection to each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Everyone gets a say in making decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We enjoy learning about our family history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A crisis helps make our relationships strong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We like talking openly with each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have reasonable expectations of each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have positive relationships with our aunts, uncles, cousins and grandparents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We are able to face daily issues confidently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have lots of good times together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We respect the roles each of us plays in the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is a feeling of safety and security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We believe love is a powerful force that keeps us together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sarcasm is not generally used	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Agree strongly	Agree	Agree somewhat	Disagree somewhat	Disagree
We wait for each other without complaining	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Life in our family is satisfying to us	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, we have enough time for each other and we enjoy the time we share together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, we have appreciation and affection for each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All in all, we value each other and are committed to our well-being as a family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We look at challenges as opportunities for growth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, we are a strong family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*We would like you to tell us whether MS has made some things more difficult for you, and how you, and your family have tried to deal with this. Please check (✓) the box that best matches your family situation as you see it.*

**2. Compared to your friends, do you think your parent's MS has affected your:**

	No	Sometimes	A lot
Participation in recreational activities (sports teams, lessons, clubs, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social activities with your friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional development (e.g. are you able to appreciate the feelings of others, are you more aware of your own feelings, have you developed ways to control your feelings, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal maturity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationships with family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical health (e.g. injuries, sleep problems, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. Overall, has your parent's MS had a positive (good) or negative (bad) affect on your:**

	Very positive	Positive	Neither positive nor negative	Negative	Very negative	Don't know
Participation in recreational activities (sports teams, lessons, clubs, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social activities with your friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship with your parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe: \_\_\_\_\_

**4. At home, are you expected to help with:**

	No	Sometimes	A lot
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for the parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for the parent with MS (e.g. giving pills, giving needles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other household activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe: \_\_\_\_\_

Please check (✓) the box that best applies to you. If it does not apply, please leave the answer blank and go on to the next statement.

**5. Compared to your friends, how would you describe your responsibilities for:**

	Much higher	Higher	About the same	Lower	Much lower
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for the parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for the parent with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of yourself (e.g. making own lunches, doing homework)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check (✓) the box that best applies to you. If the question does not apply to you, please leave the answer blank and go on to the next question.

**6. How happy are you with your responsibilities at home for:**

	Very happy	Happy	Neither happy nor unhappy	Unhappy	Very Unhappy
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for your parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for your parent with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of yourself (making own lunches, doing homework)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not at all	Very little	A bit	Quite a bit	A great deal
<b>7. How well do you understand MS?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8. How important do you think it is for children to understand this type of illness?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**9. How did you learn about MS? (please check all that apply)**

- |   |   |
|---|---|
| <input type="checkbox"/> From your parents                  | <input type="checkbox"/> From printed materials or videos from the MS Society |
| <input type="checkbox"/> From a health professional         | <input type="checkbox"/> From the Internet                                    |
| <input type="checkbox"/> From going to an education session | <input type="checkbox"/> From staff and volunteers of the MS Society          |
| <input type="checkbox"/> From going to a support group      |   |
| <input type="checkbox"/> Other (Please describe) _____      |   |

*Please check (✓) the box that best applies to you. If none apply, please leave the answer blank and go on to the next question.*

**10. As you were growing up, were you able to find information about MS that was easy to understand when you were:**

	Not at all	Very little	A bit	Quite a bit	A great deal
Age 2 – 5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Age 6 – 11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Age 12 – 18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**11. To what extent does your parent’s MS result in:**

	Not at all	Very little	A bit	Quite a bit	A great deal
Mood changes and emotional outbursts that affect you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stresses between your parents that affect you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Embarrassment about your parent’s MS symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Symptoms that make it difficult to hug each other or show affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You being afraid that you might get MS or pass it on to your own children someday	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You being afraid that your parent with MS will suddenly have to go to the hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not at all	Very little	A bit	Quite a bit	A great deal
You worrying that your parent with MS will become much sicker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulties with you participating in extra-curricular activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulties for you to do normal things with your friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulties with getting your homework done	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You feeling that you don't know what to expect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**12. Has your parent's MS been upsetting for you?**

- Never
  Occasionally
  Quite often
  All the time

**13. How did you learn to deal with your emotions about your parent's MS (check all that apply)?**

- I didn't
  From health professionals  
 From my parent with MS
  From support groups  
 From my parent without MS
  From printed materials or videos from the MS Society  
 From brothers or sisters
  From staff and volunteers of the MS Society  
 From other family members
  From the Internet  
 From friends  
 Other (Please describe) \_\_\_\_\_

**14. Families use a number of different strategies to cope with the effects of MS. In your opinion, do the following happen in your family?**

	No	Occasionally	Frequently	Doesn't apply
We talk about the emotions and fears that result from a parent's MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We talk openly about the symptoms of MS so that I can understand the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have developed ways of showing affection when physical contact (e.g. hugging) is difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We find ways to make sure that my parent's MS doesn't make it difficult for me to get my homework done	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We find ways so that the MS doesn't affect my participation in sports and extra-curricular activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

No      Occasionally      Frequently      Doesn't apply

---

We find ways so that my parents can attend and support my school activities

---

We talk openly about the extra caregiving demands that MS can put on all family members

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**15. What is the most important thing families can do to help children when their parent has MS?**

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**16. What is the most difficult thing about having a parent with MS?**

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**17. What are the things that you think could be done better by the MS Society, family, school, etc. to help children whose parent has MS?**

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*We know that families work hard so that their children can “Grow up Strong.” What would you say would help children most in the future? In each category we would like to know what you think are the three most important things.*

**18. More information for parents on: (please check the top three)**

- |  |   |
|--|---|
| <input type="checkbox"/> Facts about MS                      | <input type="checkbox"/> How to support children in giving personal or medical care to their parent with MS |
| <input type="checkbox"/> MS symptoms                         | <input type="checkbox"/> How to help your children talk to you about MS                                     |
| <input type="checkbox"/> MS therapies                        |   |
| <input type="checkbox"/> Parenting tips for families with MS |   |
| <input type="checkbox"/> Talking to your children about MS   |   |
| <input type="checkbox"/> Others (please specify) _____       |   |

**19. More information for children under 12 on: (please check the top three)**

- |  |   |
|--|---|
| <input type="checkbox"/> Facts about MS  | <input type="checkbox"/> Taking on added responsibilities when your parent has MS |
| <input type="checkbox"/> MS symptoms   | <input type="checkbox"/> How to explain MS to your friends                        |
| <input type="checkbox"/> MS therapies  | <input type="checkbox"/> How to talk to your parents                              |
| <input type="checkbox"/> Giving personal or medical care to their parent with MS | <input type="checkbox"/> How to cope with having MS in your family                |
| <input type="checkbox"/> Dealing with your own feelings                          |   |
| <input type="checkbox"/> Others (please specify) _____                           |   |

**20. More information for teenagers over 13 on: (please check the top three)**

- |  |   |
|--|---|
| <input type="checkbox"/> Facts about MS  | <input type="checkbox"/> Taking on added responsibilities when your parent has MS |
| <input type="checkbox"/> MS symptoms   | <input type="checkbox"/> How to explain MS to your friends                        |
| <input type="checkbox"/> MS therapies  | <input type="checkbox"/> How to cope with having MS in your family                |
| <input type="checkbox"/> Giving personal or medical care to their parent with MS | <input type="checkbox"/> How to talk to your parents                              |
| <input type="checkbox"/> Dealing with your own feelings                          |   |
| <input type="checkbox"/> Others (please specify) _____                           |   |

**21. What would be the best ways for providing this material? Please check the top three.**

- |   |  |
|---|--|
| <input type="checkbox"/> Written materials      | <input type="checkbox"/> CD-ROM          |
| <input type="checkbox"/> Audio (e.g. tapes)     | <input type="checkbox"/> Games           |
| <input type="checkbox"/> Video                  | <input type="checkbox"/> School programs |
| <input type="checkbox"/> Internet               | <input type="checkbox"/> Meetings        |
| <input type="checkbox"/> Other (describe) _____ |  |

**22. Please check (✓) the top three programs or services that you think would be most helpful.**

- Programs to help children learn about MS
- Support groups for children
- Recreational programs and camps for children of people with MS
- Programs to teach extended families (parents, children, aunts, uncles, grandparents) about MS
- Programs to help pull families together (parents, children, aunts, uncles, grandparents) so that they can provide more caregiving support
- Programs to pull families together (parents, children, aunts, uncles, grandparents) so that they can have fun together
- Programs to help teachers, schools and other organizations understand the challenges some children face when their parent has health problems or disabilities
- Programs to help parents develop skills for creating strong families
- Other (describe) \_\_\_\_\_

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**23. What would be the best ways for providing for this training? Please indicate the three best.**

- Written materials
- Audio (tapes)
- Video
- Internet
- CD-ROM
- Games
- School programs
- Meetings
- Other (please describe) \_\_\_\_\_

*About you and your family:*

**24. How many years ago was your parent or family member diagnosed with MS?** \_\_\_\_\_

**25. Approximately how old were you when your parent was diagnosed with MS?** \_\_\_\_\_

**26. Which parent has MS?**

- Mother                       Father                       Other (e.g. grandparent) \_\_\_\_\_

**27. What type or form of MS does your parent have, as diagnosed by the doctor?**

- |   |   |
|---|---|
| <input type="checkbox"/> I don't know             | <input type="checkbox"/> Progressive-relapsing MS |
| <input type="checkbox"/> Relapsing-remitting MS   | <input type="checkbox"/> Benign MS                |
| <input type="checkbox"/> Primary-progressive MS   | <input type="checkbox"/> Malignant MS             |
| <input type="checkbox"/> Secondary-progressive MS |   |

*Please describe who lives in your house:*

**28. Number of children:**

Number of children under 6 \_\_\_\_\_

Number of children 6 to 11 \_\_\_\_\_

Number of children 12 to 18 \_\_\_\_\_

**29. Number of Adults:**

Parent with MS \_\_\_\_\_

Parent who doesn't have MS \_\_\_\_\_

Grandparents \_\_\_\_\_

Aunts, uncles \_\_\_\_\_

Other \_\_\_\_\_

**30. What is your position in the family?**

- Only child                       Oldest                       In the middle                       Youngest

31. Your current age: \_\_\_\_\_

32. Your gender:

- Female                       Male

33. Your preferred language:

- English                       French                       Other\_\_\_\_\_

34. Where do you live?

- In Canada, specifically...
- Alberta
  - British Columbia
  - Manitoba
  - New Brunswick
  - Newfoundland
  - Northwest Territories
  - Nova Scotia
  - Nunavut
  - Ontario
  - Prince Edward Island
  - Quebec
  - Saskatchewan
  - Yukon
- Outside Canada

35. Do you live in:

- A large city (1 million or more)                       Town (under 100,000)
- Small city (100,000 to 1 million)                       Rural community

*Thank you!*





Multiple Sclerosis  
Society of Canada

## **GROWING UP STRONG SURVEY**

### **Questionnaire for ADULT CHILDREN (ages 19 and over) of parents with multiple sclerosis**

*Hello!*

*Thank you for taking the time to help us.*

*Before you start, we want you to know that the personal information you give us in this survey will be kept private. No names will be used in any presentation of the information that is collected. We won't even ask for your name!*

*The MS Society of Canada is conducting this very important survey to gather information about how parents with multiple sclerosis (MS) and their families support the emotional, social, educational, and physical development of their children. This information will be used to identify areas where additional programs or support from the MS Society could be helpful. In order to best understand this, we are seeking the input of parents who have MS and their partners, children 18 and under, and adults who grew up with a parent with MS. Each of these perspectives will be different and important. As an adult child completing this questionnaire, we ask you to think back to when you were 6 – 18 years of age and reflect on your experience growing up with a parent with MS, and what was or might have been helpful.*

*We know that all families are different, but each family has many strengths. We would like your help in understanding how your family works, whether MS has presented challenges to your family, and how your family has tried to overcome these challenges.*

*We will also ask for your ideas about how the MS Society of Canada could support families so that they can be as strong as possible and enable their children to “Grow Up Strong.”*

*There are no right or wrong answers to the 35 questions in this survey. Please answer according to how you think or feel about each question. We want to learn as much as we can from you.*

*Thank you so much for your participation!*

*We would like to know about your family and how it worked together. Please check (✓) the box that best matched your family when you were 6 –18 years of age. If the statement doesn't apply to you and your family please leave it blank and go on to the next one.*

**1. In our family ...**

	Agree Strongly	Agree	Agree Somewhat	Disagree Somewhat	Disagree
We enjoyed helping each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We liked to share our feelings with each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Responsibilities were shared in a fair way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We had a positive attitude toward life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We worked together to solve very difficult family problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We liked to give each other a chance to do new things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We liked to show affection to each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Everyone got a say in making decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We enjoyed learning about our family history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A crisis helped make our relationships strong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We liked talking openly with each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We had reasonable expectations of each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We had positive relationships with our aunts, uncles, cousins and grandparents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We were able to face daily issues confidently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We had lots of good times together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We respected the roles each of us plays in the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There was a feeling of safety and security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We believed love is a powerful force that keeps us together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sarcasm was not generally used	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Agree Strongly	Agree	Agree Somewhat	Disagree Somewhat	Disagree
We waited for each other without complaining	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Life in our family was satisfying to us	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, we had enough time for each other and we enjoyed the time we shared together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, we had appreciation and affection for each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All in all, we valued each other and were committed to our well-being as a family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We looked at challenges as opportunities for growth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, we were a strong family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*We would like you to tell us whether MS made some things difficult for you between the ages of 6 and 18, and how you and your family tried to deal with this. Please check (✓) the box that best matches your family situation as you see it.*

**2. Compared to your friends, do you think your parent's MS affected your:**

	No	Sometimes	A lot
Participation in recreational activities (sports teams, lessons, clubs, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social activities with your friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal maturity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationships with family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical health (e.g. injuries, sleep problems, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. Overall, did your parent's MS have a positive (good) or negative (bad) affect on your:**

	Very positive	Positive	Neither positive nor negative	Negative	Very negative	Don't know
Participation in recreational activities (sports teams, lessons, clubs, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social activities with your friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship with your parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe: \_\_\_\_\_  
 \_\_\_\_\_

**4. At home, were you expected to help with:**

	No	Sometimes	A lot
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for the parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for the parent with MS (e.g. giving pills, giving needles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other household activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe: \_\_\_\_\_  
 \_\_\_\_\_

Please check (✓) the box that best applied to you between the age of 6 and 18. If it does not apply, please leave the answer blank and go on to the next statement.

**5. Compared to your friends, how would you describe your responsibilities for:**

	Much higher	Higher	About the same	Lower	Much lower
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for the parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for the parent with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of yourself (e.g. making own lunches, doing homework)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check (✓) the box that best applied to you between the age of 6 and 18. If the question does not apply to you, leave the answer blank and go on to the next question.

**6. How happy were you with your responsibilities at home for:**

	Very happy	Happy	Neither happy nor unhappy	Unhappy	Very Unhappy
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for your parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for your parent with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of yourself (making own lunches, doing homework)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not at all	Very little	A bit	Quite a bit	A great deal
<b>7. How well did you understand MS when you were 6 – 18?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8. How important do you think it is for children to understand this type of illness?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**9. How did you learn about MS? (please check all that apply)**

- |   |  |
|---|--|
| <input type="checkbox"/> From your parents                  | <input type="checkbox"/> From printed materials, or videos from the MS Society |
| <input type="checkbox"/> From a health professional         | <input type="checkbox"/> From the Internet                                     |
| <input type="checkbox"/> From going to an education session | <input type="checkbox"/> From staff and volunteers of the MS Society           |
| <input type="checkbox"/> From going to a support group      |  |
| <input type="checkbox"/> Others (Please describe) _____     |  |

*Please check (✓) the box that best applies to you. If none apply, please leave the answer blank and go on to the next question.*

**10. As you were growing up, were you able to find information about MS that was easy to understand when you were...**

	Not at all	Very little	A bit	Quite a bit	A great deal
Age 2 – 5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Age 6 – 11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Age 12 – 18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**11. To what extent did your parent’s MS result in:**

	Not at all	Very little	A bit	Quite a bit	A great deal
Mood changes and emotional outbursts that affected you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stresses between your parents that affected you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Embarrassment about your parent’s MS symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Symptoms that made it difficult to hug each other or show affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You being afraid that you might get MS or pass it on to your own children someday	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not at all	Very little	A bit	Quite a bit	A great deal
You being afraid that your parent with MS would suddenly have to go to the hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You worrying that your parent with MS would become much sicker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulties with you participating in extra-curricular activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulties for you to do normal things with your friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulties with getting your homework done	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You feeling that you didn't know what to expect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**12. Was your parent's MS upsetting for you?**

- Never
  Occasionally
  Quite often
  All the time

**13. How did you learn to deal with your emotions about your parent's MS? (Check all that apply)**

- I didn't
  From health professionals
- From my parent with MS
  From support groups
- From my parent without MS
  From printed materials, or videos from the MS Society
- From brothers or sisters
  From staff and volunteers of the MS Society
- From other family members
  From the Internet
- From friends
- Others (Please describe) \_\_\_\_\_

**14. Families use a number of different strategies to cope with the effects of MS. In your opinion, did the following happen in your family when you were a child?**

	No	Occasionally	Frequently	Doesn't apply
We talked about the emotions and fears that result from a parent's MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We talked openly about the symptoms of MS so that I could understand the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We developed ways of showing affection when physical contact (e.g. hugging) was difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We found ways to make sure that my parent's MS didn't make it difficult for me to get my homework done	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No	Occasionally	Frequently	Doesn't apply
We found ways so that the MS didn't affect my participation in sports and extra-curricular activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We found ways so that my parents could attend and support my school activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We talked openly about the extra caregiving demands that MS can put on all family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**15. From your experience, what do you think is the most important thing families can do to help children when their parent has MS?**

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**16. What is the most difficult thing about having a parent with MS?**

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**17. What are the things that you think could be done better by the MS Society, family, schools, etc. to help children whose parent has MS?**

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*We know that families work hard so that their children can “Grow up Strong.” What would you say would help children most in the future? In each category we would like to know what you think are the three most important things.*

**18. More information for parents on: (please check the top three)**

- |  |   |
|--|---|
| <input type="checkbox"/> Facts about MS                      | <input type="checkbox"/> How to support children in providing personal and medical care to their parent with MS |
| <input type="checkbox"/> MS symptoms                         | <input type="checkbox"/> How to help your children talk to you about MS   |
| <input type="checkbox"/> MS therapies                        |   |
| <input type="checkbox"/> Parenting tips for families with MS |   |
| <input type="checkbox"/> Talking to your children about MS   |   |
| <input type="checkbox"/> Others (please specify) _____       |   |

**19. More information for children under 12 on: (please check the top three)**

- |  |   |
|--|---|
| <input type="checkbox"/> Facts about MS  | <input type="checkbox"/> Dealing with their emotions                              |
| <input type="checkbox"/> MS symptoms   | <input type="checkbox"/> Taking on added responsibilities when your parent has MS |
| <input type="checkbox"/> MS therapies  | <input type="checkbox"/> How to explain MS to your friends                        |
| <input type="checkbox"/> Providing personal and medical care to their parent with MS | <input type="checkbox"/> How to talk to your parents                              |
| <input type="checkbox"/> Others (please specify) _____                               | <input type="checkbox"/> Coping strategies  |

**20. More information for teenagers over 13 on: (please check the top three)**

- |  |   |
|--|---|
| <input type="checkbox"/> Facts about MS  | <input type="checkbox"/> Taking on added responsibilities when your parent has MS |
| <input type="checkbox"/> MS symptoms   | <input type="checkbox"/> How to explain MS to your friends                        |
| <input type="checkbox"/> MS therapies  | <input type="checkbox"/> Coping strategies  |
| <input type="checkbox"/> Providing personal and medical care to their parent with MS | <input type="checkbox"/> How to talk to your parents                              |
| <input type="checkbox"/> Dealing with their own emotions                             |   |
| <input type="checkbox"/> Others (please specify) _____                               |   |

**21. What would be the best ways for providing this material? Please indicate the three best.**

- |  |  |
|--|--|
| <input type="checkbox"/> Written materials             | <input type="checkbox"/> CD-ROM          |
| <input type="checkbox"/> Audio (e.g. tapes)            | <input type="checkbox"/> Games           |
| <input type="checkbox"/> Video                         | <input type="checkbox"/> School programs |
| <input type="checkbox"/> Internet                      | <input type="checkbox"/> Meetings        |
| <input type="checkbox"/> Others (please specify) _____ |  |

**22. Please check (✓) the top three programs or services that you think would be most helpful.**

- Programs to help children learn about MS
- Support groups for children
- Recreational programs and camps for children of people with MS
- Programs to teach extended families (parents, children, aunts, uncles, grandparents) about MS
- Programs to help pull families together (parents, children, aunts, uncles, grandparents) so that they can provide more caregiving support
- Programs to pull families together (parents, children, aunts, uncles, grandparents) so that they can have fun together
- Programs to help teachers, schools and other organizations understand the challenges some children face when their parent has health problems or disabilities
- Programs to help parents develop skills for creating strong families
- Others (please describe) \_\_\_\_\_

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**23. What would be the best tools for providing these programs? Please indicate the three best.**

- Written materials
- Audio (tapes)
- Video
- Internet
- CD-ROM
- Games
- School programs
- Meetings
- Others (please describe) \_\_\_\_\_

*About you and your family:*

**24. How many years ago was your parent or family member diagnosed with MS? \_\_\_\_\_**

**25. Approximately how old were you when your parent was diagnosed with MS?**

Under 6

Age 6 – 11

Age 12 - 18

**26. Which parent has or had MS?**

Mother

Father

Other (e.g. grandparent) \_\_\_\_\_

**27. What type or form of MS does or did your parent have, as diagnosed by the doctor?**

I don't know

Relapsing-remitting MS

Primary-progressive MS

Secondary-progressive MS

Progressive-relapsing MS

Benign MS

Malignant MS

*Please describe who lived in your house when you were a child:*

**28. Number of children: \_\_\_\_\_**

**29. Number of Adults:**

Parent with MS \_\_\_\_\_

Parent who doesn't have MS \_\_\_\_\_

Grandparents \_\_\_\_\_

Aunts, uncles \_\_\_\_\_

Other \_\_\_\_\_

**30. What is your position in the family?**

Only child

Oldest

In the middle

Youngest

31. Your current age: \_\_\_\_\_

32. Your gender:

Female

Male

33. Your preferred language:

English

French

Other \_\_\_\_\_

34. Where did you live as a child?

Canada, specifically...

Alberta

British Columbia

Manitoba

New Brunswick

Newfoundland

Northwest Territories

Nova Scotia

Nunavut

Ontario

Prince Edward Island

Quebec

Saskatchewan

Yukon

Outside Canada

35. Did you live in:

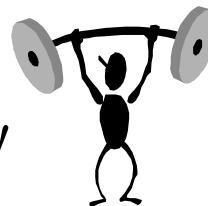
A large city (1 million or more)

Small city (100,000 to 1 million)

Town (under 100,000)

Rural community

*Thank you!*





Multiple Sclerosis  
Society of Canada

## **GROWING UP STRONG SURVEY**

### **Questionnaire for PARENTS AND PARTNERS of parents with multiple sclerosis**

*Hello!*

*Thank you for taking the time to help us.*

*Before you start, we want you to know that the personal information you give us in this survey will be kept private. No names will be used in any presentation of the information that is collected. We won't even ask for your name!*

*The MS Society of Canada is conducting a very important survey to gather information about how parents with multiple sclerosis (MS) and their families support the emotional, social, educational, and physical development of their children. This information will be used to identify areas where additional programs or support from the MS Society could be helpful. In order to best understand this, we are seeking the input of parents who have MS and their partners, children who are minors, and adults who grew up with a parent with MS. Each of these perspectives will be different and important.*

*We know that all families are different, but each family has their own strengths. We would like your help in understanding how your family works, whether MS has presented challenges to your family, and how your family has tried to overcome these challenges.*

*We will also ask for your ideas about how the MS Society of Canada could support families so that they can be as strong as possible and enable their children to "Grow up Strong."*

*There are no right or wrong answers to the 33 questions in this survey. Please answer according to how you think or feel about each question. We want to learn as much as we can from you.*

*Thank you so much for your participation!*

*We would like to know about your family and how it works together. Please check (✓) the box that best matches your family situation. If the statement doesn't apply to you and your family situation, please leave it blank and go on to the next one.*

**1. In our family...**

	Agree Strongly	Agree	Agree Somewhat	Disagree Somewhat	Disagree
We enjoy helping each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We like to share our feelings with each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Responsibilities are shared in a fair way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have a positive attitude toward life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We work together to solve very difficult family problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We like to give each other a chance to do new things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We like to show affection to each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Everyone gets a say in making decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We enjoy learning about our family history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A crisis helps make our relationships strong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We like talking openly with each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have reasonable expectations of each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have positive relationships with our aunts, uncles, cousins and grandparents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We are able to face daily issues confidently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have lots of good times together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We respect the roles each of us plays in the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is a feeling of safety and security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We believe love is a powerful force that keeps us together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sarcasm is not generally used	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Agree Strongly	Agree	Agree Somewhat	Disagree Somewhat	Disagree
We wait for each other without complaining	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Life in our family is satisfying to us	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We are happy as a family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, we have enough time for each other and we enjoy the time we share together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All in all, we value each other and are committed to our well-being as a family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We look at challenges as opportunities for growth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, we are a strong family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*We would like you to tell us whether MS has presented challenges to you and your family situation, and how your family has tried to meet these challenges. Please check (✓) the box that best matches your family situation as you see it.*

**2. Compared to your friends with children, has the parent's MS had an influence on your children's:**

	No	Occasionally	Frequently
Participation in recreational activities (sports teams, lessons, clubs, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendships with people their own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social activities with their friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal maturity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship with family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical health (e.g. injuries, sleep problems, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. Overall, has the impact of MS been a positive (good) or negative (bad) affect on your child's:**

	Very positive	Positive	Neither positive nor negative	Negative	Very negative	Don't know
Participation in recreational activities (sports teams, lessons, clubs, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendships with people their own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social activities with their friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship with you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe: \_\_\_\_\_  
 \_\_\_\_\_

**4. At home, are your children expected to help with:**

	No	Sometimes	A lot
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for the parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for the parent with MS (e.g. giving pills, giving needles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other household activities because a parent has MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please describe: \_\_\_\_\_  
 \_\_\_\_\_

Please check (✓) the box that best applies to you. If the question does not apply, please leave the answer blank and go on to the next statement.

**5. Compared to your friends' children, how would you describe the level of responsibility your children take for:**

	Much higher	Higher	About the same	Lower	Much lower
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for the parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for the parent with MS (e.g. giving pills, giving needles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Independently caring for themselves (making own lunches, doing homework)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check (✓) the box that best applies to you. If the question does not apply to you, leave the answer blank and go on to the next statement.

**6. How happy do you think your children are with their level of responsibility for:**

	Very happy	Happy	Neither happy nor unhappy	Unhappy	Very Unhappy
Household tasks (laundry, house cleaning, gardening, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Babysitting for brothers and sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal care for the parent with MS (help with bathing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical care for the parent with MS (e.g. giving pills, giving needles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing the house (e.g. paying bills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Independently caring for themselves (making own lunches, doing homework)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**7. Have you told your children about MS?**

- Yes  No

**8. How old were they when you first discussed MS with them? \_\_\_\_\_**

	Not at all	Very little	A bit	Quite a bit	A great deal
<b>9. How well do you think your children understand MS?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>10. How important do you think it is for children to understand this type of illness?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**11. How did your children learn about MS? (check all that apply)**

- |   |   |
|---|---|
| <input type="checkbox"/> From the parents                   | <input type="checkbox"/> From printed materials or videos from the MS Society |
| <input type="checkbox"/> From a health professional         | <input type="checkbox"/> From the Internet                                    |
| <input type="checkbox"/> From going to an education session | <input type="checkbox"/> From MS Society staff and volunteers                 |
| <input type="checkbox"/> From going to a support group      |   |
| <input type="checkbox"/> Other (please describe) _____      |   |

*Please check (✓) the box that best applies to you. If none apply, please leave the answer blank and go on to the next question.*

**12. Were you able to find materials that children at various ages could understand?**

	Not at all	Very little	A bit	Quite a bit	A great deal
Age 2 – 5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Age 6 – 11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Age 12 – 18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**13. To what extent does MS in your family situation result in:**

	Not at all	Very little	A bit	Quite a bit	A great deal
Mood changes and emotional outbursts by the person with MS that affect the children in the household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stresses between parents that affect the children in the household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not at all	Very little	A bit	Quite a bit	A great deal
Embarrassment about the symptoms of MS that affects the children in the household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Symptoms that makes it difficult to hug or show affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fear by your children that they will get MS themselves or pass MS to their children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety that when the children get home from school the parent with MS will have gone to the hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worry that when the children get home from school the parent with MS will have become much sicker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limiting the ability of children to participate in extra-curricular activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limiting the ability of children to do normal kinds of things with their friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limiting the ability of children to complete their homework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The children not knowing what to expect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**14. How do the children learn about how to deal with their feelings about their parent's MS? (check all that apply)**

- |   |   |
|---|---|
| <input type="checkbox"/> From the parent with MS      | <input type="checkbox"/> From support group                                   |
| <input type="checkbox"/> From the parent without MS   | <input type="checkbox"/> From printed materials or videos from the MS Society |
| <input type="checkbox"/> From brothers or sisters     | <input type="checkbox"/> From the Internet                                    |
| <input type="checkbox"/> From other family members    | <input type="checkbox"/> From MS Society staff and volunteers                 |
| <input type="checkbox"/> From friends                 |   |
| <input type="checkbox"/> From health professionals    |   |
| <input type="checkbox"/> Other (Please describe)_____ |   |

**15. Families use a number of strategies to cope with the impacts of MS. In your opinion, which of the following does your family use?**

	No	Occasionally	Frequently	Doesn't apply
We talk about the emotions and fears that result from a parent's MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have developed ways of showing affection when physical contact (e.g. hugging) is difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No	Occasionally	Frequently	Doesn't apply
We work together so that the MS doesn't affect their school work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We work together so that the MS doesn't affect their participation in sports and extra-curricular activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We have found ways to support and/or attend school activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We talk openly about the extra caregiving demands that MS can put on all family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We talk about the emotions and fears that result from a parent's MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**16. What has worked best in your family to support your children to "Grow Up Strong?"**

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**17. What has presented some of the greatest challenges for you and your children?**

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**18. What are the things that you think could be done better by the MS Society, family, schools, workplaces, etc?**

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*We know that families work hard so that their children can “Grow Up Strong.” What would you say would help children most in the future? Please check the three most important things in each category:*

**19. More information for parents on: (please check the top three)**

- |  |   |
|--|---|
| <input type="checkbox"/> Facts about MS                      | <input type="checkbox"/> Supporting children to talk about their feelings related to MS |
| <input type="checkbox"/> MS therapies                        | <input type="checkbox"/> How to support children in a caregiving role                   |
| <input type="checkbox"/> Parenting tips for families with MS | <input type="checkbox"/> How to help your children talk to you about MS                 |
| <input type="checkbox"/> Talking to your children about MS   |   |
| <input type="checkbox"/> Others (please specify) _____       |   |

**20. More information for children under 12 on: (please check the top three)**

- |   |   |
|---|---|
| <input type="checkbox"/> Facts about MS   | <input type="checkbox"/> Taking on added responsibilities when your parent has MS |
| <input type="checkbox"/> MS symptoms  | <input type="checkbox"/> How to explain MS to your friends                        |
| <input type="checkbox"/> MS therapies   | <input type="checkbox"/> How to talk to your parents                              |
| <input type="checkbox"/> Providing personal and medical care for their parent with MS | <input type="checkbox"/> Coping strategies  |
| <input type="checkbox"/> Expressing their feelings                                    |   |
| <input type="checkbox"/> Others (please specify) _____                                |   |

**21. More information for teenagers over 13 on: (please check the top three)**

- |   |   |
|---|---|
| <input type="checkbox"/> Facts about MS   | <input type="checkbox"/> Taking on added responsibilities when your parent has MS |
| <input type="checkbox"/> MS symptoms  | <input type="checkbox"/> How to explain MS to your friends                        |
| <input type="checkbox"/> MS therapies   | <input type="checkbox"/> Coping strategies  |
| <input type="checkbox"/> Providing personal and medical care for their parent with MS | <input type="checkbox"/> How to talk to your parents                              |
| <input type="checkbox"/> Dealing with their feelings                                  |   |
| <input type="checkbox"/> Others (please specify) _____                                |   |

**22. What would be the best ways for providing this material? Please indicate the three best.**

- |   |  |
|---|--|
| <input type="checkbox"/> Printed materials      | <input type="checkbox"/> CD-ROM          |
| <input type="checkbox"/> Audio                  | <input type="checkbox"/> Games           |
| <input type="checkbox"/> Video                  | <input type="checkbox"/> Meetings        |
| <input type="checkbox"/> Internet               | <input type="checkbox"/> School programs |
| <input type="checkbox"/> Other (describe) _____ |  |

**23. Please check the top three programs or services that you think would be most helpful.**

- Meetings or support groups for parents in similar situations
- Support groups for children
- Recreational programs and camps for children of people with MS
- Programs to teach extended families (cousins, aunts, uncles, grandparents) about MS
- Programs to help pull families together (parents, children, aunts, uncles, grandparents) so that they can provide more caregiving support
- Programs to pull families together (parents, children, aunts, uncles, grandparents) so that they can have fun together
- Programs to help teachers, schools and other organizations understand the challenges some children face when their parent has health problems or disabilities
- Programs to help parents develop skills for creating strong families
- Other (describe) \_\_\_\_\_

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**24. What would be the most effective approach for this training? Please indicate the three best.**

- Printed materials
- Audio
- Video
- Internet
- CD-ROM
- Games
- Meetings
- School programs
- Other (describe) \_\_\_\_\_

*About you and your family:*

**25. How many years ago was MS diagnosed?** \_\_\_\_\_

**26. What type or form of MS do you have/does your partner have, as diagnosed by the doctor?**

- |   |   |
|---|---|
| <input type="checkbox"/> I don't know             | <input type="checkbox"/> Progressive-relapsing MS |
| <input type="checkbox"/> Relapsing-remitting MS   | <input type="checkbox"/> Benign MS                |
| <input type="checkbox"/> Primary-progressive MS   | <input type="checkbox"/> Malignant MS             |
| <input type="checkbox"/> Secondary-progressive MS |   |

*Please describe who lives in your house.*

**27. Number of children:**

Number of children under 6	_____
Number of children 6 to 11	_____
Number of children 12 to 18	_____

**28. Number of Adults:**

Person with MS	_____
Partner/Spouse	_____
Grandparents	_____
Others	_____

**29. Your current age:** \_\_\_\_\_

**30. Your gender:**

- Female                       Male

**31. Your preferred language:**

- English                       French                       Other (please specify)\_\_\_\_\_

### 32. Where do you live?

- In Canada, specifically...
  - Alberta
  - British Columbia
  - Manitoba
  - New Brunswick
  - Newfoundland
  - Northwest Territories
  - Nova Scotia
  - Nunavut
  - Ontario
  - Prince Edward Island
  - Quebec
  - Saskatchewan
  - Yukon
  
- Outside Canada

### 33. Do you live in:

- A large city (1 million or more)
- Small city (100,000 to 1 million)
- Town (under 100,000)
- Rural community

*Thank you!*



## **14 Appendix 3**

### **Focus Groups Facilitator's Guide.**



Multiple Sclerosis  
Society of Canada

## ***Growing Up Strong: Supporting the Children of Parents With Multiple Sclerosis Focus Groups with Children 12 and Under***

### **Facilitator's Guide**

*The following is provided as a guide for Facilitators regarding the format and content of the forthcoming children's focus groups. The guidelines are provided to promote consistency across the groups in the approach and the information collected. At the same time, it is recognized that the issues raised by the children may vary from group to group. This will be influenced by the group composition – gender, ages and experiences of the children. The purpose of the focus groups is to better understand the perspective of the children. Thus we want to encourage flexibility on the part of facilitators to elaborate and explore the ideas expressed by the children, in addition to the questions identified below. A variety of media will be available to facilitate expression – paper, markers, flip charts etc. Feel free to use any of these as well as other creative outlets if they are helpful. Please ensure that these are returned with the audiotape of the session in order that they can be included in the data analysis.*

**It is anticipated that the Focus Group will be approximately one hour in length.**

#### **INTRODUCTION: (about 10 minutes)**

1. Introduce self.
2. Introduce purpose of the group:
  - Really glad that the children came today
  - They are special and have experienced something that most children have not – having a parent who has MS
  - We want to learn from them what that is like in order that we can help other children who also have a parent with MS
  - They are part of a large project that is taking place across Canada
  - We are going to talk about all sorts of things related to having a parent with MS
  - There are no right or wrong answers.
  - Everything that they say will be kept in confidence (their name will not be connected with it). You may want to have a short discussion to ensure that all understand what confidentiality means.

- We will be together as a group for about an hour. If they don't want to participate at any time or have questions at any time they can say so.
  - Their parents will be in the next room (having treats too!)
  - Ask children if they have any questions.
3. Ask each of the children to introduce themselves, how old they are, whether it is their mom or dad who has MS.
  4. Involve the children in a short discussion on setting the ground rules, for example: only one person talks at a time; no one tells anyone else that their idea is wrong or stupid; everyone gets a chance to say something etc. You may want to write these on the flip chart. Everyone is responsible for making sure the group sticks to the rules.

Describe your job – to ask questions, make sure you understand what they mean, keep track of time to make sure all the questions get answered, sometimes write things down. You are also going to tape record the discussion to help you remember accurately the things that have been said.

### **FOCUS GROUP QUESTIONS:**

5. **The Children's Understanding of MS** (*about 5 minutes*)
  - What does having MS mean to them?
  - How did they learn about MS?
  - Do they think children should be told when their parent has MS?
6. **Compared to their friends whose parent doesn't have MS, has their life been different? In what ways?** (*about 15 minutes*)
  - Related to school
  - Related to the things they do outside school (teams, lessons, time with friends)
  - Related to their responsibilities at home
  - What is the best thing about being a child whose parent has MS?
  - What is the most difficult thing for a child whose parent has MS?
7. **If their best friend found out that their mom or dad has MS:** (*about 20 minutes*)
  - What are the most important things your friend should know?
  - What would they want to tell their friend about having MS in the family?
  - What is the most important thing that their friend's parents could do to help them?
  - What could organizations such as the MS Society do to help them?
  - What could schools do to help them?
  - Are there things like videos, DVDs, CDs, Websites, books or other things that would be helpful?

**8. Are there any things that you would like to know about having a parent with MS?**  
*(Approximately 10 minutes)*

The Client Services Director/Manager/Coordinator could be invited to provide information and referral in response to children's questions.

**WRAP-UP: (about 3-5 minutes)**

9. Please thank the children again for their participation. Emphasize how important it is that we learn about what they think and feel. It will be helpful to other kids across Canada. Offer that if anyone has any questions or something they would like to say to you in private that you will stay behind a few minutes after the group leaves.
10. Offer children the available gifts. Juggling balls and children newsletters are available ("Keep S'Myelin" – for English speaking children – and "les nerfs !" for French speaking children)