

## Parents' Experience of Pediatric Onset Multiple Sclerosis

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## Executive Summary

### Introduction

Although the body of research on pediatric onset Multiple Sclerosis (POMS) has been growing, few previous studies describe the experience of the parents of the youths who have POMS. We conducted a qualitative interview-based study to describe the parent experience, with the goal of informing clinicians who provide medical and psychosocial care to this population, sharing findings with parents of recently diagnosed children, and generating hypotheses for further research. This executive summary captures the core information from the study, but we advise readers who cannot read the entire report to skim the document for the transcript excerpts in italics for a genuine understanding of parents' experience. Chapter summaries are also available at the end of most chapters.

### Method

To help develop an interview protocol, a focus group was convened of parents of youths with MS who are now young adults. We asked about parents' reaction to their child's diagnosis, knowledge of MS prior to and following diagnosis, the balance between monitoring and intrusiveness, worry management, thoughts about the future, impact on family and couple relationships, and support received from family, friends, and health care providers. An appendix to this report presents the protocol that was developed based on the focus group and the authors' clinical experience.

Parent participants were recruited from the Pediatric MS Centers at Massachusetts General Hospital and Boston Children's Hospital. To be eligible for the study, the young person with MS had to be under age 18 at the date of the interview and have a confirmed

diagnosis of MS by one of the pediatric MS specialists at the two hospitals. The second author conducted all 21 interviews between April 2014 and April 2015. Interviews were audio-recorded and transcribed by a professional service. Analysis files were created for the following topics: 1) pre-diagnosis, 2) receiving the diagnosis, 3) adapting to life with MS (which focused greatly on communication about the illness to others), 4) treatment, 5) family life, 6) school, 7) living with MS over time (which focused substantially on thoughts about the future), and 8) advice to other parents. The analysis files were read carefully and themes were identified that were addressed by most or all of the interviews.

### **Families' Experience Prior to the Diagnosis**

Families experienced considerable stress in the time after children became symptomatic but before MS was diagnosed. Families with children with MS often went through months of uncertainty and anxiety before a definitive diagnosis was made. Parents often reported intense shock, fear, and puzzlement that their active, healthy children could suddenly develop a mysterious, potentially disabling disease. A number of parents reviewed their children's past experiences and had observed episodes of fatigue, malaise, or school difficulties that they thought, in retrospect, may have been early signs of the illness.

Symptoms were often misunderstood at first as minor, everyday occurrences such as sleeping in a bad position, or as children being mischievous or malingering or lacking concentration. When symptoms persisted or additional symptoms became evident, parents realized something more serious was wrong. Initially, most consulted pediatricians or other health care providers in their local community (e.g., optometrists or ophthalmologists) or went to hospital emergency departments. What followed was a

prolonged period (often 7 to 14 days) of often difficult medical tests, a series of negative results, more common diagnoses considered and rejected, and significant uncertainty about what was happening to their child. Typical was a process of moving from primary care physicians to neurologists or other specialists, and then eventually to the two centers specializing in pediatric MS in which this study was based. In some cases, the possibility of MS was not apparent for a considerable amount of time. In other cases, the MS was raised as a possible diagnosis early in the process, but a substantial amount of time elapsed before the definitive diagnosis was made. While the diagnostic process could take weeks to months, several families experienced a single, long, dreadful day that began with a fairly standard medical consultation near their home and ended with a hospitalization at a major medical center and a diagnosis of MS. Occasionally physicians discovered lesions characteristic of MS by coincidence when MRIs were obtained for other medical conditions.

### **Receiving the Diagnosis**

Parents often found receiving the diagnosis of MS overwhelming. Most had not realized that children and adolescents could develop MS. They reacted with shock, sadness, desperation, fear, disbelief and denial. Parents imagined severe outcomes: A majority of parents discussed the fear of their child having to use a wheelchair. Family members consoled themselves in a variety of ways, for example, thinking that it could be worse (e.g., a brain tumor), and hoping that the child's youth would protect them from the worst consequences of the illness. Parents developed greater acceptance over time, buoyed by support from their family and friends and by their children's resilience and capabilities despite the illness.

In most cases, parents received the diagnosis during a hospitalization following the appearance of neurological symptoms, but occasionally parents received the news when the child was at home or received it over the telephone. We heard several stories of physicians having a family meeting which included the young person with MS, parents and even other family members in the clinic or hospital room. In some cases, this meeting was carefully planned ahead of time by HCPs and parents. In other cases, parents' report of how the young person with MS was told did not suggest that either they or their HCPs had reflected on how to do it.

Families made very different decisions about to whom they should disclose the diagnosis, ranging on a continuum from considerable privacy to unrestricted openness. Which friends, neighbors, co-workers and others to tell was an individual decision for each family. The support and assistance gained from talking to family and friends was quite helpful. One father was pleased to learn about several acquaintances who had MS but were successfully coping with it.

There were challenges in talking about it as well: dealing with their own sadness, figuring out how to explain an illness they understood poorly themselves, countering others' negative scenarios about the illness, and dealing with others' sadness and fear. The challenges could be greater if family members believed that they were at risk genetically. Young persons with MS varied in their decisions about disclosure. Some talked only to their closest friends, while others were completely open; one youth made it the subject of a class project. Many worried that they would be stigmatized, or felt self-conscious or even ashamed of having the illness. They often wanted to be treated like everyone else. Sometimes they simply grew tired talking about it.

## **Impact on the Family**

For most youths, the physical effects of MS impacted their functioning in several areas: peer and family relationships, schoolwork, sports, and leisure activities. Several experienced fear, frustration, embarrassment, self-consciousness, irritability, anger and/or worry about the future. Some withdrew from peers. Yet a number of adolescents were reticent and did not want to talk about the illness; some parents worried their children were in denial. Still other parents thought that their children's lack of distress about the illness was simply a reflection of their resilience, trust in their parents, or trust in God.

Parents talked about their anxiety about the possibilities of relapses and progression of the disease. Some said they found themselves worrying about a relapse even when their children had mild everyday symptoms. Several parents were reluctant to show their emotional reaction to the illness, not wanting to risk exacerbating the MS by further stressing their child. Several parents worried that they were responsible for the MS. One father blamed himself for his child's illness because his mother had MS and he thought he had contributed a gene. Another searched her mind for what she might have done wrong during the pregnancy and another worried that her cooking might be at fault.

The vast majority of our interviewees were mothers, and MS often placed a significant burden on them. Sometimes it could be hard on marriages if mothers were taking on a disproportionate share of the responsibility of thinking about and managing the illness. MS could strain already difficult relationships between separated or divorced parents, but the sensitive and supportive response of both parents to their ill child could actually ease tensions. On the other hand, one mother credited the family's response to MS as a factor in keeping her and her husband together. MS could be hard on the siblings

as well. They worried not only about their brother or sister with MS, but sometimes also about contracting MS themselves. Sometimes they were jealous about the attention their sibling with MS received.

We asked if MS had had any positive effects on the family. Many parents said it brought the family closer together and helped them develop greater empathy. The idea that “*at any given moment, things could change*” made them value family relationships in the moment and make them a priority. More than one parent talked about how they had gained added respect from their children for the hard work they have done because of the MS, and the sacrifices they have made. It is not surprising that several parents reported that their children’s MS changed the way they parented. Yet many parents felt that they had established a solid base in how they parented before the MS that the illness did not alter.

One challenge parents had to deal with is the overall stress MS placed on the family and how this stress could contribute to conflict with their children. One parenting issue was setting reasonable expectations given what the youths could and could not do to take care of themselves, which was often hard to determine. Another challenge was deciding how much independence youths with MS should have.

### **Treatment**

Uncertainty about the effects of treatment and concerns about side effects sometimes made it difficult to make treatment decisions. Typically, young people with MS, their families, and their neurologists worked together to decide on treatment. Parents took their children’s feelings and opinions seriously, and sometimes decision-making mainly involved the young person and their neurologist. Some parents chose to be very

actively involved in decision-making, while other parents look to their doctors for recommendations.

The biggest challenge with treatment was the difficulty of the subcutaneous or intramuscular injections administered either by parents or by youths themselves. Several young people with MS experienced pain, burning, welts, or bruises from the injections. Some youths and their parents experienced anxiety and disgust over the injections, and several parents felt distressed watching their children receive them. The difficulties with injections could disrupt the treatment and cause families to stop or switch medications. Some families had problems with the injections but were reluctant to join a clinical trial which included oral medications because of the possibility of receiving a placebo if one were assigned to the control group. Auto-inject devices were generally helpful but did not eliminate the problems, and one youth found the auto-injector more painful. The flu-like side effects of the interferon beta-based injectable medication could be problematic, sometimes causing youths to miss school. The welts and bruises caused by injections, and the equipment families had to carry for injections when traveling threatened their privacy about the illness. A few families discontinued injections temporarily (once in favor of a naturopathic treatment) when the youth was feeling well. All the young persons with MS were receiving either injectable or oral medication at the time of the study.

Several families appreciated their neurologist's knowledge of research in making treatment recommendations. Many families also did their own reading and Internet searching, although their research did not always provide clear answers. One parent expressed concern about whether the treatments that she reported had been developed through research on Europeans and European-Americans would be effective for her

African-American son. Parents' worry that their child might experience serious side effects sometimes made treatment decisions difficult.

Disease-modifying medication prevented some of the exacerbations of MS, but not all, and there was a great deal of trial and error. Several youths had tried as many as three or four medications over a period of months to years. The experience could be gruelingly repetitive: each new attempt could be followed by a resurgence of MS symptoms and an additional course of treatment with IV methylprednisolone. Sometimes a disease-modifying treatment (DMT) would appear to be effective for a period of months or even years and then suddenly, for no apparent reason, stop working. Management of pediatric MS involved regular MRIs to check for disease activity. Parents often worried that the MRI would reveal new lesions, while an MRI with no new disease activity was a reason to celebrate.

### **The Impact of MS at School**

A number of the young persons with MS had cognitive changes that often led to subtle and complicated impairments in their learning. Fatigue from MS was also a problem at school. A number of youths missed school because of hospitalization, many because of symptoms of the illness, and a few because of the side effects of medication. One mother talked about how teachers would expect her daughter to make up work at home after missing days in school; they would not realize her symptoms would make this impossible. Parents had to manage most of the communication with the school about their child's MS, and this was a substantial ongoing demand. Some youths were reluctant to have the family share any information with the school because they did not want to be treated differently. Occasionally students would take time off from school because of the

illness or avoid other school expectations, perhaps simply because of being overwhelmed, and it was sometimes difficult to determine if their request was legitimate. In other cases, students pushed to return to school and parents had to hold them back to protect their health.

Many students had 504 plans and/or Individual Education Plans (IEPs) that provided accommodations to compensate for the effects of MS. Some plans were responsive and implemented effectively, some schools had unresponsive plans, and some plans might have been effective but were not fully implemented.

In most families, their children's friendships at school were not affected, or were strengthened since the diagnosis of MS. Most youths were able to continue socializing with their peers as before, but had to miss certain opportunities just as they sometimes had to miss school. In a few cases, peers actively supported the youth in responding to the illness, for example, by participating in an MS Walk.

### **Adaptation, Resilience and Concerns about the Future**

Most youth described in the study were on disease-modifying treatment and doing well. Most youths and their families had adapted to the illness over the course of months or years and had overcome the worst stress of the illness. Several youths were able to excel in school or sports or a part-time job despite the MS. Often there was a mix of resilience and suffering. Most parents had a number of family members who had supported them with their love, time and material resources, which parents found essential. A few parents had extended family members who were not engaged or supportive, and they looked to friends for support. The development of treatment for MS

has given families hope and helped them cope. Religious faith was also an important resource for several families.

Most families had benefited from the National Multiple Sclerosis Society (NMSS), though the degree to which they engaged with the NMSS varied. Financial and informational support from the MS Society were important resources. Some youths and their families had met new friends through the MS Camp, the MS Walk or other NMSS resources. They discovered they were not alone and learned from other youths' experiences. MS events could give youths an opportunity to feel that they were successful and contributing despite their illness. Involvement in the MS Society seemed for most families to develop months or even years after the diagnosis and initial treatment, when so much of their time and energy was spent dealing directly with the illness.

Some families had little or no contact with the MS Society, either through lack of knowledge or by choice. One mother felt that the local support group available to her was not helpful because its members were adults with MS. Sometimes youths and/or parents resisted contact with the MS Society out of a wish to be normal and not have to think more about the illness. One concern was the effect on the youth of seeing other youths with MS with more disabling conditions. Some families found it helpful to connect with others affected by MS through personal connections or social media rather than the NMSS.

We asked parents what their major concerns for the future were about their child's MS. Because the course of MS is unpredictable and every youth faced the possibility of progressive impairment, parents' overriding concern was the possibility that the illness would in the future rob their children of independence, self-sufficiency and quality of

life. One concern was that parents would not be around to take care of their children in the future. Some families' concerns about the future focused on whether medication would be effective and affordable. Another concern was children's ability to undertake and enjoy normal young adult experience such as dating, going to college, having children and pursuing careers they wanted. Parents were also concerned about whether their children would make choices that maintained their health when they became more independent. Some parents had hope for the future because of ongoing research on MS and several volunteered that they were wishing for a cure, though one mother was discouraged, saying "*I don't think they'll ever find a cure.*"

### **Advice to Other Parents**

We asked parents for their advice to other families affected by pediatric MS. Several discussed that seeking support and avoiding "what ifs" were especially helpful in the very beginning. Many parents reported that they handled the unpredictability of their child's illness by focusing on the present ("*taking it day by day.*") and being as flexible as possible, to avoid making the family more fearful and focused on the illness. A number of parents advised showing a positive attitude and keeping their fear to themselves, so they do not negatively affect their children.

Parents recommended working closely with health care providers; this included involving their child in the communication with neurologists. Many study participants recommended that families involve themselves in the community of families affected by pediatric MS, to find people to talk to and provide and receive support. Most parents would advise newly diagnosed families to be hopeful. They drew their hope from education about MS, current research, their faith, and watching their child adapt to life

with MS with grace and courage. They talked about the families' capacity to adapt to the illness, which, as one put it, "*is not the end of the world*" and their realization that, despite everything, "*life can be good.*"

### **Conclusions and Recommendations**

The families affected by pediatric multiple sclerosis whom we interviewed face significant challenges, but in the course of meeting these challenges, have demonstrated notable resilience. Despite the difficulties families endured, many of them were doing well and to some degree thriving at the time of the interview. Disease-modifying treatment appears to play an important role in the continued well-being of most young people with MS in these families. The pediatric MS centers and the National Multiple Society received considerable praise from the parents interviewed for their role in responding to the illness and supporting children and families.

Our findings suggest several recommendations. In order to minimize the long, demanding, and confusing diagnostic odyssey of reaching a diagnosis of MS, we urge the NMSS, advocacy organizations, and professional organizations like the American Academy of Neurology, and the Consortium of Multiple Sclerosis Centers work to educate pediatricians, ophthalmologists, emergency room physicians, and other HCPs about pediatric MS. House staff on pediatric neurology wards should also be educated to increase their awareness of the needs and wishes of parents, particularly concerning the disclosure of MS to their children. Additional support could be provided by school consultation liaisons provided by hospitals or the NMSS who could educate schools about MS, advise schools on how to respond to symptoms, participate in planning meetings and support parents. Successful cognitive-behavioral interventions developed

for adults dealing with the difficulties of administering injectable medications could be adapted for youth with MS and their families. Because many youths with MS are adolescents and emotional and behavioral issues characteristic of that life stage shape families' response to the illness, training and experience with this age group is essential in the professional response to pediatric Multiple Sclerosis. Families living with MS should be the unit of treatment with an emphasis on the needs of parents; this might require additional staff. The NMSS and other advocacy organizations need to promote interaction of parents who have a child with MS, including in-person contacts, on-line connections, social media communication, and/or a yearly congress combining parents, young people, researchers and clinicians. Pediatric MS centers, the NMSS, and medical centers and staff should respond to the need to provide mental health services for youths with MS and their families. Future research should study more thoroughly the anxiety of parents of youths with MS, the effect on parenting and marital relationships, and parents' attitudes about treatment of pediatric MS, particularly about participating in clinical trials.

### **Dedication**

We dedicate this work to the parents who gave of themselves and their time, disclosing emotional and personal perspectives on their experience. Also to the health care providers who are in the forefront of caring for children and adolescents with MS, their parents, and their families. We are grateful for the support of the National Multiple Sclerosis Society for funding this research, under Health Services Research Pilot grant PP205.

## Chapter 1

### Introduction and Methodology

#### Introduction

It is estimated that the onset of Multiple Sclerosis (MS) occurs before the age of 18 in 2.7-10.5% of cases.<sup>1,2</sup> Although a growing literature has reported on the psychosocial sequelae of pediatric onset multiple sclerosis (POMS),<sup>3</sup> little is known about the experience of the parents of children and teens who have MS. Several members of the research team have years of experience in a pediatric MS center, and this experience indicates that the diagnosis of a chronic, potentially disabling neurological disease in one's child is extremely difficult for parents, and that management of the illness in the context of child and adolescent development is challenging. Parents of chronically ill children have been shown to experience distress and a sense of vulnerability with regard to the illness<sup>4</sup>, as well as marital discord.<sup>5</sup> Parents with disabled children have been shown to experience higher levels of stress and lower levels of well-being than parents of non-disabled children.<sup>6</sup> One challenge is for parents to help their children manage the illness without becoming overbearing and overprotective.<sup>7</sup>

Although the body of research on pediatric onset MS has been growing, there are few previous studies which describe the experience of the parents of youths with MS. Messmer Uccelli et al<sup>8</sup> compared 15 couples who had a child with MS to a convenience sample of other parents "personally known by the researchers", utilizing measures of mood, coping, marital satisfaction and sense of competence in parenting. Interviews with parents in the target group revealed that the parents were under-informed about MS, but functioning well. Parents of children with MS were less satisfied with their parenting role

than parents of healthy children, had a lower sense of parenting competence, and had higher depression scores, although anxiety scores did not differ. Questions can be raised, however, about the validity of any contrast between parents of children with MS and a comparison group of the researchers' acquaintances. For the parents of children with the disease, greater knowledge of MS correlated with greater satisfaction with the couple relationship, greater communication between the members of the couple, and a stronger sense of parental competence. The authors recommend increased education and psychosocial support for families living with pediatric MS.

Thannhauser<sup>9</sup> interviewed six young people with MS in one study and seven in another<sup>10</sup>, and also interviewed their parents in every case but one. The first study described the nature of the grief that the young persons experienced, and detailed the dynamics of peer relationships for youths with MS. The young persons struggled with how the injectable medication regimen interfered with their social life, and experienced both problems in peer relationships due to the illness, and significant support from close friends. Of interest, however, was a description of the struggle the young people with MS experienced with injectable medication, and their perception that the discomfort involved was minimized by health care providers. The second described the multiple losses experienced over time from the illness, and the ways in which they coped, including not letting the MS define them, maintaining normalcy, developing expertise on the illness, selectively disclosing aspects of their experience, and developing ways to make meaning of their new lives. Thannhauser did not, however, report separately on the views, perceptions, and experience of the parents who participated—presumably what was learned from parents simply augmented the knowledge gained from the child.

Hinton and Kirk<sup>11</sup> interviewed 31 parents together with 21 children and adolescents with MS from 23 families in the UK. They described the child and parental experience of the diagnostic process, and barriers to a prompt diagnosis. The families reported that health care providers often misinterpreted symptoms, that pediatricians had too little awareness of pediatric MS, and that health care professionals were reluctant to make the diagnosis of MS. They recommended that HCPs be more responsive to family reports of symptoms, make appropriate referrals, and facilitate timely diagnosis and treatment of young people with MS.

In studies of the psychosocial impact of POMS, parents have been used as valuable informants on the functioning of their children. Discussion of the impact of POMS on parents was beyond the scope of these studies, which include MacAllister, et al.,<sup>12</sup> Weisbrot et al.,<sup>13</sup> Goretti et al.,<sup>14</sup> and Till et al.<sup>15</sup>

Since the small body of research on parents of children with MS relies on questionnaires, and is largely not focused on the experience of parents, it is appropriate to utilize an open-ended research methodology which would generate hypotheses about the experience of parenting a child or teen with MS. We conducted a qualitative interview-based study to describe their experience, with the goal of informing clinicians who provide medical and psychosocial care to this population, and generating hypotheses for further research. Parents of children under 18 years old who have been diagnosed with Multiple Sclerosis were recruited at the Pediatric MS Centers at Massachusetts General Hospital and Boston Children's Hospital and invited to participate in the study.

## **Methods**

### **Focus Group**

We employed a collaborative research model, in which the subject population is actively involved in the design of the research protocol. This model, known as community-based participatory research, has been well utilized in research and program design with families living with chronic illness.<sup>16</sup> A focus group of parents of youths with MS who are now young adults was convened to provide responses to and feedback on interview questions proposed by the researchers and to generate new interview questions that would capture the experience of parents of POMS. Focus group parents were recruited through the Greater New England Chapter of the National Multiple Sclerosis Society; the society maintains a mailing list of parents of children with MS.

We asked parents' reaction to their child's diagnosis, knowledge of MS prior to and following diagnosis, the balance between monitoring and intrusiveness, worry management, thoughts about the future, impact on family and couple relationships, and support received from family, friends, and health care providers (HCPs). We audio recorded the focus group discussion, and it was transcribed. Based on feedback from the focus group participants, the interview protocol was revised. The final interview protocol is in an appendix to this report.

### **Recruitment**

Parents were eligible to be interviewed for the study if they had a child under the age of 18 with a confirmed diagnosis of MS based on the revised McDonald criteria.<sup>17</sup> Parents meeting these eligibility criteria were sent a letter inviting them to call if they wanted to participate in a one-hour semi-structured interview. The letter recruited parents

generally, and mothers, fathers, stepparents and live-in partners were eligible to participate, either singly or in couples. If parents did not call within two weeks in response to the letter, they were recruited by telephone. If there was still no response, they were called again within approximately a month of their child's subsequent appointment or recruited during a clinic visit. Most families agreed to participate. A small number declined due to the difficulty in traveling long distances. Most parents were enthusiastic and supportive of the study.

### **Interviews**

The interviews were arranged according to the parents' convenience. In most cases, the interviews took place at Massachusetts General Hospital (MGH) or Boston Children's Hospital (BCH) and were scheduled to coincide with follow-up visits to the clinic. In some cases, the interviews were conducted in homes, restaurants, and hotel rooms, based on participant preference. The second author conducted a total of 21 interviews between April 2014 through April 2015. Interviews were audio-recorded and transcribed by a professional service.

MGH and BCH are tertiary care hospitals, and draw patients from surrounding states, and sometimes from great distances. Many of the children of parents interviewed for this study initially saw health care providers in their local communities. Typically, they underwent diagnostic procedures there and, in some cases, they received the diagnosis of MS before their first appointment at MGH or BCH. Descriptions of interactions with community health care providers as well as with MGH and BCH staff are included.

All names and other identifying information have been removed to protect the privacy of the families. When a child's name was spoken in an interview, it appears as "[Name]" in the text. When the name of a health care provider was spoken, it is indicated as "[MD]", and a specific hospital as "[Hospital]." Direct quotes from parents are presented in italics. Consistent with the wishes of many people who have MS and other chronic disorders, as well as the recommendations of the American Psychiatric Association<sup>18</sup>, we use terms to describe our population that emphasize that they are persons, not simply patients. The terms used include, "young people with MS," "youths," and "children and adolescents with MS." Finally, we wish to emphasize that our interviewees were parents, who reported on both their own and their children's experience, and we did not interview any of the young people with MS. All comments about the youths with MS are based on parent report only.

### **Participants**

Across the sample of 21 cases, 18 mothers were interviewed as well as 1 father and 2 couples. When asked their racial and ethnic identity, parents self-identified as European-American in 12 cases, Latino in 4 cases, Asian in 2 cases, Portuguese in 2 cases, and African-American in 1 case. The interviewees' average age was 43.8. Most of the young persons with MS in these families were girls (15 cases), and their average age was 14.76. The number of months since their diagnosis of MS ranged from less than 1 to 81, with a median of 20 months. Cases were about evenly divided between MGH (11 cases) and BCH (10 cases).

## **Data Analysis**

Interview transcripts were analyzed using an adaptation of Braun and Clarke's<sup>19</sup> method of thematic analysis. We first read all the transcripts thoroughly to develop a holistic understanding of families' experience and to identify additional topics that were not initially anticipated. We then sorted sections of the text of the transcript into the topic areas covered by the interview protocol, and produced analysis files for the following topics: 1) pre-diagnosis, 2) receiving the diagnosis, 3) adapting to life with MS (which focused greatly on communication about the illness to others), 4) treatment, 5) family life, 6) school, 7) living with MS over time (which focused substantially on thoughts about the future), and 8) advice to other parents. These topics correspond roughly to the chapters in this report, although there was some editorial re-organization to enhance the flow of the report. Each analysis file was a Microsoft Word document consisting of a table in which each row presented the information for a given family. Three columns were included, presenting 1) the interview number, 2) relevant text on that topic from that interview copied and pasted from the interview transcripts, and 3) notes summarizing each family's response on that topic, based on the transcript material. Thus each analysis file consisted of 63 cells, primarily of text (21 rows for the 21 families x 3 columns = 63). The analysis files were read carefully and themes were identified that were addressed by most or all of the interviews. Notes describing the range of content within a theme were made from the analysis files, and both these notes, the analysis files, and, as needed, the interview transcripts were then referred to in writing each chapter.

## Chapter 2

### The Pre-diagnosis Experience

*“They had tested her for every kind of thing that they could imagine and everything was coming back negative, negative, negative.”*

Multiple Sclerosis in children is uncommon and often difficult to diagnose. Symptoms of pediatric MS are sometimes mistaken for other, more common illnesses. It sometimes takes considerable time to receive a definitive diagnosis. Among the children of the parents interviewed, the following were presumptive diagnoses or were considered diagnostically before it was determined that the child had MS: brain tumor, Lyme disease, influenza, viral meningitis, inner ear problems, and fallen arches (for difficulties walking). Some parents expressed bitterness about diagnostic delays and the possibility of misdiagnosis. One mother said:

*...doctors have a tendency to give this 18 second diagnosis and just tell, especially nowadays they just tell you what they think it is and then prescribe you some pills to medicate a symptom or problem that gives you 10 other symptoms, and I don't like that.*

Families with children with MS often went through months of uncertainty and anxiety before a diagnosis was made. They offered detailed accounts of the events, feelings and thoughts they experienced during this time period.

### Symptoms at Onset

Initial symptoms varied widely. They included numbness, difficulty walking, muscle weakness, vision loss, fatigue, headache, loss of appetite, dizziness, loss of balance and falling, incoordination, tremor, seizures, cognitive dysfunction, and difficulties with verbal fluency. The children reported to their parents that their body felt

wrong in different ways. Many youths had difficulty with simple functions that we normally take for granted such as maintaining a normal facial expression or putting on their clothes. These symptoms often made it impossible for youths to carry on their normal lives. As one parent reported,

*...she became a baby again, like-- she lost control of her legs, her arms. We had to help her walk. ... she had to learn how to walk, all over again...She just collapsed and she had no control of anything, even like her bladder, nothing, you know.*

Not surprisingly, symptoms often caused youth considerable anxiety about their appearance, what their peers would think about them, and whether they could meet expectations at school.

Most of the youths had no previous history of neurological illness, and parents were unprepared. Symptoms sometimes mimicked common conditions and were misinterpreted by parents in the beginning. One parent initially thought, for example, that numbness was caused by sleeping in a bad position and another that a bad taste in the mouth was a result of spoiled food. What made it more difficult is that symptoms like fatigue, numbness, tingling or other sensations are invisible, hard to specify and easy to minimize. Some parents thought at first that symptoms were minor, and they urged children to persevere despite the symptoms interfering with their activities.

*He played [in a two-day sport tournament]. And I remember sleeping that night that he was very restless; like all night long he just tossed and turned, tossed and turned, which was unordinary for him, especially after playing three games all day in the heat. So I just thought that was weird. But I just kind of brushed it off again. The next morning, we get up and he's like "I don't feel good, I have a headache." He was very crabby, et cetera, et cetera. So, the terrible mother that I was, I made him play the last game. I said "you need to get out there, you need to play." Because I thought he didn't want to play because he just didn't want to play. In*

*hindsight, I learned he was scared to death of what was happening to him, because he didn't know what was happening to him.*

Sometimes parents briefly misconstrued symptoms and thought youths were being mischievous, malingering or not concentrating. The youths themselves sometimes minimized or hid their symptoms, and this contributed to the misunderstanding. Parents expressed considerable guilt for not recognizing the symptoms more promptly. Here are several mothers' accounts:

*I'm like, "[Name], you done yet?" And she's like, "I'm trying to get on my pants." And she only had one leg in and then she was standing up and trying to put on the other one, but she couldn't balance on that one. So I'm like, "Stop playing around." You know, this is why I feel bad, because I thought she was just acting like a baby, you know.*

*She was so weak...I was getting irritated with her a lot...because I didn't realize what it was. I thought she was just being clumsy. And then she would make excuses. She's good at making up excuses and playing up whatever is bothering her at that point in time so that she could get out of doing things that she didn't want to do.*

*So you know how you sleep, you sleep like this, your hand gets numb so I told her to shake it off, wait. And unfortunately I waited three weeks because no pain, no nothing, just-- so finally like three weeks, I took her to her doctor's... So now if she has anything, I don't wait because I felt guilty; very, very guilty.*

*You know, teenagers are funny; they're hard. They like to stay in their room...It was like, you wanted to kind of help her get out of her room...but she didn't want any help. She just kind of doing things her own way...But now I wonder if part of that were issues that were going on with MS at that point. You know? She used to sleep a lot, and I used to think it was just the lazy teenager. You look back and think, 'shame on me'.*

### **The Process of Seeking a Diagnosis**

Parents quickly realized something was wrong when symptoms persisted or additional symptoms arose. They consulted pediatricians, optometrists or ophthalmologists (in the case of visual symptoms) or went to hospital emergency

departments. Typically, the diagnostic process began in one medical setting local to the family, but ended at the pediatric MS centers at Massachusetts General Hospital or Boston Children's Hospital. One family switched from another medical facility to a specialist at an MS clinic based on their own research about treatment options.

One family's experience is representative in a number of ways. The daughter complained of intermittent dizziness, which the family initially thought might be related to a concussion she had suffered a year before. She also had headaches, which they initially thought were allergy-related. They consulted a pediatrician in July, who did blood work and other medical tests but did not find anything to explain the symptoms. The symptoms persisted. Then their daughter experienced some spasticity and they sought another medical consultation on the Friday of Labor Day weekend. Tests revealed only a vitamin deficiency. They had a follow-up appointment on the Tuesday after, and the doctor almost did not recommend further diagnostic work because the daughter laughed when she reported her sensations of tingling, and her mother interpreted her behavior as a psychological defense mechanism. Nevertheless, the daughter was given an MRI that day, which revealed demyelinating lesions that allowed the doctors to make the diagnosis of MS.

In some cases, the possibility of MS was raised early on, but long periods of time elapsed before the definitive diagnosis was made. One boy had persistent headaches and numbness that led the family to consult a physician, but the test results could not differentiate between a viral illness or MS. Only at a follow-up appointment six months later, when, ironically, the boy happened to be asymptomatic, were lesions found that led definitively to a diagnosis of MS. Another girl taken to the pediatrician for headaches had

a range of symptoms that led immediately to a hospitalization, but MS was only one of several possible diagnoses. She was discharged with some symptomatic improvement but no definitive diagnosis. A month later she was re-hospitalized with major motor problems and only then was the diagnosis definitively made. The delay and uncertainty in diagnosis was often frustrating for families, as one parent explained:

*I felt really bad for the doctor because I wasn't very nice to him because he said he possibly has MS. It's kind of like being possibly pregnant. You know, you either are or you aren't, like what-- really, how does this work? And he's like he's got possible MS. And I couldn't look at him. I couldn't look at him because I just knew I was welling up and I didn't want him to see me... I just got up and I walked out and shut the door and I lost it. I started bawling and I'm at the front desk asking... "I want another doctor in there. I don't think he knows what he's doing. He's saying he has possible MS. You don't possibly have things."*

In another case, the young person was hospitalized for several days, underwent a series of sometimes difficult medical tests, was treated with steroids, and then was discharged without a diagnosis. Her mother and father described it in this way:

*They had tested her for every kind of thing that they could imagine and everything was coming back negative, negative, negative... She was admitted for three days... They had no clue. We left the hospital not knowing. They thought maybe it could have been like a neurological-something. They wanted to say viral, because they had no clue. Well, that was very upsetting to all of us, I think, not knowing...and being there three days and not finding anything out... Just not knowing what's going on. And her, not knowing what's going on with your body.*

While the diagnostic process could take weeks to months, a few families experienced a single, long, dreadful day that began with a fairly standard medical consultation near their home and ended with a hospitalization in a distant major medical center and a diagnosis of MS. One family consulted an optometrist about their daughter's vision problem, who, after observing inflammation of the optic nerve, (optic neuritis),

referred them immediately to an ophthalmologist. The ophthalmologist understood this condition to be related to MS, especially given a family history of the illness, and scheduled an MRI for the following week. He then talked to colleagues and became concerned enough to track them down leaving the parking garage and tell them to go to the local hospital immediately. The local hospital was concerned enough to refer them for hospitalization at Boston Children's Hospital that very night.

Several parents told stories of children who experienced painful or anxiety-provoking diagnostic procedures. As one parent said, *"In that week, it was the worst for us because they did so many test[s] and they were hurting her."* One parent told about their daughter's painful lumbar puncture. It was repeated twice after the medical professionals had left their daughter's arm bruised because they had trouble finding a vein. The room was hot and parents felt that they would pass out. Despite this stress, the youth was unfazed according to the parents because her religious faith was so great.

Parents had a range of thoughts and feelings during this pre-diagnostic phase. They were shocked and fearful and sometimes felt guilty if they had initially overlooked symptoms. Some, at first, developed alternative explanations, with the idea that some other illness was causing the symptoms. One parent initially thought that perhaps her child caught an illness from exposure to passengers on a cruise ship. They often reported intense puzzlement that their active, healthy children could suddenly develop a mysterious, potentially disabling disease.

*We were traveling [on a family vacation]. Who knows what she could have been exposed to? Maybe it's something that mimics it. Maybe it's something that looks like it. I just kept thinking that there was no way.*

A number of parents reviewed their children's past experiences and saw episodes of fatigue, malaise, or school difficulties that they thought, in retrospect, may have been early signs of the illness:

*[Discussing earlier school difficulties] Like her tantrums were, she would do anything to make people repulsed by her, like not want to be around her at all, and throw her shoes. They had her hospitalized her last big [behavioral] episode, and she went through all of this clinical therapies and people trying to figure out what was wrong with her. I honestly think, knowing what I know now, that she had MS back then and it just was misdiagnosed.*

Several parents cited their children's courage in facing the pre-diagnostic phase as a factor that helped give the parents strength. One parent cited an instance in which their son made the doctor laugh by pointing out the limitation of the medical team using the same cognitive test with the same answers every day.

## **Summary**

Youths had a wide variety of symptoms that led families to seek treatment, and often endured a long diagnostic process with a number of difficult diagnostic procedures and mistaken diagnoses preceding the diagnosis of MS. On the other hand, the diagnosis sometimes was made over the course of one long, grueling day beginning with a visit to a local health care provider and ending with a hospitalization and diagnosis of MS at a major medical center. The process was baffling and very emotionally challenging for the youths with MS, their parents and the rest of the family. The long period of not knowing was difficult for youths and their families, but the family's persistence and resilience throughout the difficult pre-diagnostic phase was clear.

### Chapter 3

#### Receiving the Diagnosis

*“How can one kid be healthy one day and then diagnosed with something so serious the next?”*

Receiving the diagnosis of MS was often overwhelming. Parents described the experience with language such as,

*“I was in shock”, “devastating”, “desperate, desperate, desperate”, “sad,” “a slap in the face”, “It was emotional. We felt her pain on that”, “hurtful and hard to accept” “grim outlook”, “I was just in a daze that day.”*

Fear was a major part of the reaction:

*“Every time when you find out your child... comes down with ...any type of disease that there is no cure, you get very scared. And we were, and we still are” and “The fear of it all, it still has not gone away...”*

Most parents initially imagined the worst possible outcome. One parent said to herself:

*“Oh my God, is this like a death sentence?”* The majority of parents, at some point in the interview, discussed the fear of their child having to use a wheelchair, even though there was no question about wheelchairs or motoric deficits in the interview protocol.

Parents and family members consoled themselves in a variety of ways. One brother said, *“I looked it up, mom. It could be worse. It could be a brain tumor.”* One mother thought that her daughter’s youth itself would help protect her from the most devastating forms of the disease. Family members also reported being consoled by information from health care providers that MS was not as severe for children as for adults, that different treatments with some promise of success were available, and that medical science on MS was advancing. All parents who were interviewed reported that

they had developed ways to accept and cope with the diagnosis over time, even though the disease usually continued to be challenging.

Prior to their child's diagnosis, most parents knew little about MS. Like most people, and many health care providers, they had not realized that children and adolescents could develop MS. But most parents knew that MS is a very serious disease, and could be severely disabling. This contributed to the confusion and anxiety parents felt at the time of diagnosis. One reaction was disbelief:

*How can one kid be healthy one day and then diagnosed with something so serious the next?*

Some parents experienced denial at first.

*I'm not sure I believed any of it at that time. All I was thinking was, 'No, this is a big mistake.'*

Parents described developing greater acceptance over time, particularly as they saw how capable their children were despite the illness. One parent described it in this way:

*Yeah, it was hard for me to believe that this was happening to her that, you know- and then I started accepting the situation and then in a way, I didn't want to really hear what would be the symptoms because I was afraid of it. Now I'm very open-minded and I just take it day by day. ... she still can move, walk and do stuff. You know? Just do what she needs to do.*

In some instances, there had been a family history of MS prior to the child's diagnosis. That made parents more knowledgeable about MS, but also more concerned. One parent had a sister who had very disabling MS and was concerned that her child would think that her course of illness would be the same.

## **Communicating the Diagnosis**

There was considerable variation in how parents were delivered the news of the diagnosis and how youths were told. In most cases, parents received the diagnosis during a hospitalization, but occasionally parents received the news when the child was at home. The diagnosis was sometimes given directly to the young person by health care providers, but in most cases parents told their children. We heard several stories of physicians and health care providers having a family meeting in which they communicated the diagnosis. This meeting typically included the child, parents and even other family members in the clinic or hospital room. In some cases, this meeting was carefully planned ahead of time by HCPs and parents. In one case, the mother told the neurologist that she did not know how to tell her daughter, and the two agreed that the physician would introduce the diagnosis to the daughter with MS. In other cases, parents' report of how the child was told did not suggest that either they or their HCPs carefully planned how to communicate the diagnosis.

Sometime parents felt that the process of communicating the diagnosis to the child did not go well. One mother reported a dilemma related to being a single parent. A physician entered her son's hospital room alone to break the news of the diagnosis. She was the only one with her son and did not want to leave his side, yet she wished there had been other medical staff available so she could have a private conversation with the physician without having to leave her son alone. Two stories suggest the risk of delivering the news over the telephone. One parent received such a call at work, and said,

*Never, never, ever call someone at work, because the first time I saw wheelchairs.*

Another parent was contacted on her mobile telephone while driving; the physician suggested waiting to talk, but the parent regretfully reported that she insisted on hearing the news at that point. The result was that the mother received the shocking news while she was driving and, in her shock, revealed the diagnosis to her daughter with MS, who was in the car with her. Even under the best circumstances, a telephone call could lead to the young person learning the diagnosis inadvertently, triggered by hearing the distress in parents' voices when they heard the diagnosis from the physician.

Other families received the diagnosis after a long period in which MS had been mentioned as a possible diagnosis while one by one other possibilities and mimics had been ruled out. When the final diagnosis came, these families were expecting it. As one parent said,

*...everything was leaning towards that, so we weren't surprised, you know?*

Another parent described the process in this way:

*Because we'd been testing for it, when all these issues happened to [Name], they basically told me in the beginning it was two things. It could be MS, which they were hoping it wasn't...or it could be a Lyme disease issue. So, when the conversation happened with [MD], I wasn't in shock. It was just like a normal conversation because we had done so many tests and we already ruled out Lyme disease that I knew what else could it be? Because they told me that in the beginning, that it was one of two things. So, when they told me it wasn't Lyme disease, they had to do further testing because MS is so hard to diagnose, I just knew. I just knew.*

### **Youths' Reaction to the Diagnosis**

According to the parents interviewed, the youngsters reacted to the diagnosis in different ways, depending on such factors as their age, level of cognitive development,

and temperament. Some youths showed a good deal of distress, crying and becoming sad, depressed or angry. For one girl, it was as if somebody had cursed her and she believed God had punished her. One girl asked her father if she was going to die.

Other youths, however, showed little apparent distress. *“I was more worried than she was”*, one mother said. *“She took it like a trooper”*, said another. *“He is more worried about me than him[self]”* said a third. And another parent reported:

*So we just said, you know, “You have Multiple Sclerosis and you have some lesions in your brain.” And she was just like ... “Okay, whatever.” We could have said, “You have a toothache,” she would have been, “Okay, whatever.” So, yeah. I mean, she took it totally in stride.*

One mother described her daughter as scared but trusting her parents to protect her. One daughter helped maintain her positive approach by avoiding learning about the possible negative outcomes of the illness and concentrating on being normal. Like many teen-agers everywhere, some teen-agers were laconic, and parents could not easily tell how they felt: *“My son, unless your pants are on fire, he sometimes wouldn’t even tell you that’s going on. And that’s just how some kids are.”*

Some youths were too cognitively immature to understand the illness fully. One mother explained this:

*She knew she’s sick, she knows. She knows she has to take medicine. She knows she has to take vitamin D. She knows that she has to eat well. I don’t think she knows-- she has grasped yet the disease itself. You know what I mean? Like, maybe now she’s understanding a little bit. I tried to explain to her a little bit. But she’s not going to understand the way me and you would understand it, like that-- she just-- to me, I feel like she just knows that she’s sick. Or that her insides are different than others and she’s not the only one. I make sure I tell her that.*

### Seeking More Information

Several parents took active steps to get more information after they received the diagnosis. Some communicated concern that doctors be absolutely certain about the diagnosis:

*I just wanted to double, triple, quadruple check. I wanted to make sure they look at every avenue and every avenue's clean.*

Some sought second opinions: in some cases, the diagnosis was not made by a specialist in MS and the parents then consulted a pediatric MS center for the second opinion. Some read literature extensively: several mentioned the helpfulness of the written materials doctors provided, and several searched the internet for information, as did some youths themselves. Seeking information was helpful but could have a downside as well; some parents were frightened or disheartened by the worst-case scenarios they found online. One doctor warned a parent *not* to go to the Internet for information. As one parent put it:

*[After] reading every single possible piece of literature out there on it, I just realized that no one knows enough -- why it happened, what causes it and how to permanently treat it.*

A parent also noted that the utility of the literature is limited for families, because MS manifests itself so differently across youths with MS and its course is unpredictable. The sense of unpredictability of how MS will affect a given youth was difficult at this stage for a number of families. As one parent said:

*You almost can't compare symptoms from one person to another because they're so different between everybody. And expectations, you don't know what to expect because you don't know where it's going to hit.*

### Perceptions of Health Care Providers at the Time of Diagnosis

When asked about their health care providers' helpfulness at the time families received the diagnosis, parents almost universally felt that HCPs responded to families' needs compassionately and professionally. Responsiveness was very important to these families and they were often extraordinarily grateful when they received it:

*I love Dr. [MD]... he like almost embraced us, I think, as like a family member. He was awesome. He took time-- he wasn't even working one day he came to the hospital. He was working at a clinic, which is down the road from the hospital and he knew we were there and he said, "You know, did they show you the new MRI? Did they do... No, I didn't see that yet." He goes, "Well, when I'm done with my shift here, I'll be up." He's been amazing.*

*Everybody was amazing. I think the staff at [Hospital], the doctors, even down to like the-- just the interns were even really-- they were there every morning. I think they came to see her like five times a day and was checking constantly to see if any of her symptoms had changed. But they were just so, like, incredible. And I still, even now to this day, if I call...they're really, really good about being like just cognizant of when I call, they're just really diligent about getting back to me. And it's just really-- it makes it for a better relationship between [Name], myself and the doctor, and the nursing staff to try to help us through certain things that happen.*

Some parents specifically cited the role of Boston teaching hospitals in their appraisal:

*I think we're very fortunate to live in this part of the world to have access to the hospitals that we do...I have friends, when they get sick, and I'm like, "Go to Boston. Go to Boston." Like, they're up in these local hospitals. And not that they're bad places, but like we have access to state of the art medicine, you know? So, I'm always-- I'm going to Boston if I get sick.*

*You know, being a teaching hospital there was also a lot of interns coming in and asking her questions, a lot of the same stuff. And so she just got a kick out of that, that she constantly had this stream of visitors coming in. You know, I just found the professionalism unparalleled. There was always somebody to walk us through the next step or answer questions or provide follow-up or just checking in to see if things were going okay.*

But the latter mother also noted a disadvantage of being at a teaching hospital:

*...it's a teaching hospital and so they had somebody kind of learning... the spinal tap completely and utterly failed and I had to call a halt to it because [Name] was just hysterical. And then it took me a good hour and further sedation for [Name] to just bring her down out of that. And so I made it very clear that no more practicing spinal tap on my child and she needs to be put completely out and it needs to be done by a physician who's done it more than never. So that was the only frustrating piece for me.*

Health care providers generally received praise for providing information, answering questions and telling parents what to expect. One parent reported that their neurologist helped them manage their fear; she quoted the doctor as saying:

*I think you need to hear some positive things and not look at the worst scenario.*

One parent's appreciation of the information was tempered by an awareness of what medical science itself does not know about MS:

*...all the information that I think we don't have, the doctors don't have, too... What can cause MS? The doctors don't know that.*

A number of parents said that it was helpful to hear from doctors that the prognosis was not necessarily dire, and that several medications had been developed that were promising for youths with MS. Physicians explained to families that every case was different. One parent said that the presence of the health care providers helped the family talk about the illness, by putting "*the elephant [of the illness] in the room.*" One mother explained the following about her child's neurologist:

*...he doesn't make us feel like it's a hopeless-- and I don't feel like it's a hopeless situation for my son right now.*

The physician's assistance was critical given how little parents knew about MS at the time of diagnosis. One parent said:

*And that's when she told us what it was and what we would have to do. And at that point, it was just-- let's just do what she tells us because we have no idea what we're dealing with.*

Several families mentioned that the literature they received at this point was informative and helpful.

But praise was not universal. One mother felt that the health care providers were not straight with her about what the illness was and how severe it could be:

*I would rather hear the worst case scenario first so that I am mentally prepared for what is to come next than for you to sugarcoat it for me, or give me a bunch of scientific words that you know that I'm not going to understand and trying to make it seem like everything is going to be okay when you know that it's probably not... They never said MS. They always used demyelination. What the hell is demyelination? They said there is like three forms of demyelination that she could have and they gave me the lists of what they could be. And the last day I was there, and I didn't find out that she actually had MS until two, three weeks into [the youth's stay at a rehabilitation hospital that followed her initial hospitalization].*

Another mother was angry that a medical staff member divulged the need for a more extensive hospital stay to the youngster in a thoughtless, ill-timed way, disrupting the mother's plan to tell her child thoughtfully. Another family felt that they received little attention after getting the diagnosis; once they were told they were not asked how they felt and not educated sufficiently about MS:

*"And then when I have to sign paper to take her to the room, for the room, they didn't-- they talked to us about me signing the paper, but they didn't even ask me how I feel about that. It was hard for me. They didn't even sit, they just tell us that we have to sign this paper."*

Physicians and families invested considerable time and energy in seeking the diagnosis and treating the immediate symptoms; pursuing and receiving the diagnosis was intense. Afterwards what physicians could do for their child sometimes seemed

underwhelming in contrast. Here is how one mother and father described their experience:

*Mother: For me, they could have told me little by little. They just came and laid it out.*

*Father: Yeah they just dropped the bomb right there.*

*Mother: And then they left and that's it.*

Another parent said,

*I think I just felt being discharged and not having a follow up for six weeks was kind of-- You're given like a notebook and you just, like most people with an internet access, all you do is just read and think worst case scenario. I just had so many questions."*

She wished she had received more information about what was normal and what should lead to concern:

*...for the next few weeks anything that happened I was like, 'Oh my god, she's having a relapse. Oh my god.'" [She never realized that] "you could have symptoms all the time but it's not a relapse."*

Two parents did not feel prepared to administer injections or infusions at home and wished they had more training.

Payment for care was sometimes an issue. Two parents were unhappy that medical facilities raised issues of payment when they were trying to deal emotionally with receiving the diagnosis. One said:

*They were worried about also the payment. I didn't have [Medicaid] at the time, so they were also worried about that. So I was like, "Okay, like choke me over here." Because, I'm trying to-- how you call it? Digest what you just told me and then now you're throwing me with, like, that I owe you for the-- it was just all like too much for me. But thank goodness, everything got straightened out, but still.... Like, it was more about how was I going to pay for that visit, those five days... I know everybody got to get paid, whatever, but that just wasn't what I needed to hear, wanted to hear at all. Even in those days, like come at me after. Let me digest first*

*what's going on with my daughter. How am I going to pay for the rest of her life for her medical bills? Forget about these five days, what about for the rest of her life?*

### **Summary**

Receiving the diagnosis of MS was often overwhelming for parents as well as the youths with MS, though some youths showed little apparent distress. Parents reacted with shock, fear, disbelief and sometimes temporary denial. They imagined the worst possible outcomes. How parents and youths were told the news varied. Sometimes doctors and parents put substantial thought into how to break the news to youths, and in other cases, the accounts we heard did not suggest that there was a special process of telling the child. Sometimes parents felt that the process of communicating the diagnosis to the child did not go well – youths seeing the parent's reaction to hearing the news over the telephone was problematic. Parents actively sought more information about the illness. Health care providers were almost universally helpful at the time parents received the diagnosis, though occasionally parents were disappointed when they felt that elements of the care were not handled sensitively, for example, helping parents transition from diagnosis to ongoing care and payment issues.

## Chapter 4

### The Impact of Pediatric Multiple Sclerosis on the Family

*“Let’s all do this together. Let’s get on board and let’s try to get healthy”*

Pediatric Multiple Sclerosis can have a significant physical impact on the well-being of affected youths and an overwhelming emotional impact on the whole family. But parents and children demonstrated considerable ability to adapt to life with the illness. This chapter reports what parents told us about the emotional impact of the illness on their child and the rest of the family, how the family communicated about the illness, and handled parenting the affected youngster. Most of what we heard was retrospective: a large majority of the families in our study were well past the initial stage of the illness, and most youths and their families were managing reasonably well at the time of the interview. Some youths were still struggling at the time of the interview. Families’ adaptation and resilience in response to the illness are discussed in Chapter 7.

#### Emotional Impact on the Youth with MS

For most youths, physical symptoms of MS impacted their functioning in several areas of their life: peer and family relationships, schoolwork, sports and leisure activities. “Her whole life changed,” one mother said. Several of the youth had struggled emotionally with MS. A number of parents described how their youths experienced fearfulness, frustration, embarrassment, self-consciousness, irritability, and anger. Youth with MS worried about the effects of MS on their school life and especially what it meant for their relationships with peers. A few parents talked about youths withdrawing from or avoiding peer contact because of their concern about what they could not do with peers or

what peers would see. Youth become distressed not only about the current effects but about what MS meant for their future. One parent described the experience of her son, whose MS diagnosis followed previous diagnoses of diabetes and a seizure disorder:

*He tells me now his body hates him. He never used to talk like that. He's like, "My body hates me, Mom. My body hates me," you know. But he never used to talk like that before MS, even when he had diabetes, it wasn't any body issue. It was just life. Now he's like, "My body hates me."*

Yet not every parent reported that a son or daughter had expressed negative feelings about the MS. A number of parents also talked about how reticent their adolescents were to talk about the illness. Here are two parents' descriptions:

*And he's not one of these kids so far that's come out and said, "Why me? What did I do wrong" type thing. He might have said it to himself, but he has never been very vocal towards me or any of my family members in saying, "What did I do wrong to be dealt these cards?" Like I say, he is a great kid but he's very private in a lot of aspects.*

*Well, when I try to talk to [my daughter] about it, she doesn't want to talk about it at all. She just wants to go off and play and not deal with it at all...And if we start to talk about it, she gets upset and leaves.*

Some parents were concerned about their children's lack of expression regarding the illness. One parent thought her son was "in denial." Another parent said the following:

*I worry that she doesn't talk about it. I think in the very near future, I think having some sort of therapist would be very good for her just to get some of her feelings out there about whatever's going on. It's something big to deal with, whether she wants to admit it or not.*

Our interview method was not designed to provide an assessment of the psychological impact of MS on the children and adolescents themselves. Nevertheless, it is reasonable to infer, as some parents we interviewed suggested, that reluctance or

unwillingness to talk about the illness meant that MS had been an uncomfortable topic for many youths.

Still other parents talked about how resilient their children were and how little emotional impact they felt the MS had on them. In a previous chapter, we reported how some youths showed little apparent distress when they received the diagnosis of MS, and this characterized their reactions throughout the family's experience of MS. One mother explained her unperturbed daughter's philosophy for accepting the illness: She said to me, "It's better that I have it because I'm young, I could take care of myself. You're old. You can't do that." One mother reported that her daughter had such faith in God that she was totally unshaken by the diagnosis:

*Her faith is so big that she was normal [when she received the diagnosis] ...yeah. She says she has God and she has a family that was there and she was okay. She always says that. She's very positive. To her, this is nothing.*

### **Impact on Parents**

In an earlier chapter, we talk about how parents reported that they were shocked and often felt devastated by their child's diagnosis of pediatric MS. In this section, we focus on what family life was like once they had engaged in treatment and were learning to live with the illness. At this stage, the emotional impact of pediatric MS on parents could still be substantial. Parents talked about feelings of depression and constant anxiety about the possibilities of symptoms, relapses and progression in the disease. Even parents who had seen their children respond well to treatment continued to worry about relapses. Some talked about wondering if every symptom of common childhood illnesses could be a sign of an MS relapse. Parents could not feel emotionally free of MS regardless of how well their child was doing.

*I think the emotional part of it is always going to be there. I don't think that is ever going to go away. I think that's one of the things that's really hard. But you just kind of go on with life and you have to have a positive attitude.*

One thought that troubled several parents was that they were somehow responsible for the MS. Sometimes they drew conclusions that were understandable, but not supported by science. One father blamed himself for his child's illness because his mother had MS and he thought he had contributed a gene that led to MS. One parent said:

*It was something we thought we had prevented because we thought we did all the right things. I thought I did all the right things when I was pregnant.*

Another mother thought her cooking might have been the cause:

*Why, when, how, and who and where'd it come from. How did you get it, you know? Trying to think back, like, even the doctor, he had asked me, like how do you cook your meat, do you-- and I'm like, oh my gosh, I burn my meat. Like, I don't-- [laughter] I'm so, like, I don't like anything raw. Even my steak is well done.*

Parents struggled to understand why their child developed MS, and volunteered that they wish they had been struck by the illness rather than their child, as one mother explains:

*I ask why of her and not of me. And sometimes, I don't want to believe it. It's like a bad dream. ... You want to believe it, but you can't still and then you ask why, why your kids. Why we have to go through all this. There's a lot of questions that you ask and then you don't have answers.*

Several parents were reluctant to show their children their own emotions about the MS, particularly because they feared exacerbating the effect of MS by further stressing their child. One mother said she felt depressed, but said *"I try to control myself because I ... I have to help her."* One father said this:

*If I can make him feel as relaxed as possible...knowing stress is not good for the disease...I try to back off it as much as possible. That's why I bite*

*my tongue quite a bit in life and try to keep smiling and try to keep moving...*

Adding to the emotional impact on parents was the enormous stress of managing the illness and its treatment. Pediatric MS placed great demands on parents. The stress of involvement with medical institutions, working with health care providers, managing diagnostic procedures and treatments, communicating with other family members, and dealing with school personnel could be overwhelming. The list of things to do was unending, and caused disruption in parent's lives. Some children experienced multiple hospitalizations requiring parents to spend hours at their child's bedside, and overnight stays could last days to weeks at a time. The sheer number of appointments could be challenging to arrange. Travel time to go to medical centers for appointments was often substantial—one family moved several hundred miles simply to be closer to treatment. Parents needed to keep track of voluminous amounts of information and deal with increased costs and paperwork.

Even at home the illness placed extra demands on parents. As we will see in a later chapter, pediatric MS required parents to spend considerable time working with schools to find an appropriate educational plan for their child. One parent had to drive her son back and forth from school at odd hours because of the shortened day he needed. Parents had to manage obtaining and administering medication, and were more often the ones giving the injection than youths themselves. Parents often had to find ways to adapt to the demands of treatment: One mother could not arrange for her son to get injectable medication from a nurse at home because it was not allowed for a minor. Parents were continually required to interrupt their activities and take time to meet the demands of the illness.

Here are several parents' descriptions of dealing with pediatric MS:

*[9]: I feel like there is just always something to do, phone calls to make, appointments to schedule, appointments to drive to, the cost of the copayments and all that sort of stuff... And just thinking long term I'm thinking, "Is this always going to be like this?"*

*[16]: I am a one-woman team. I'm the mom, the dad, the grandmother. He's sick, I'm home. He got a doctor's appointment, I'm home. I make sure I schedule the prescriptions. I manage the medications ... and I have no life. Like, I don't come out here, I don't have friends, I don't go out at night. Me and my son hang out.*

*[10]: And I said to [her son's physician], I go, "I've been so out of sorts these last six months because I've been trying to take care of myself, that I'm like, when's his MRI?" [The physician] looks at me, and goes, "Oh, my God, you're usually telling me when things are." I go, "I know, I'm like out of sorts." It's a full-time job sometimes. It truly is. And then when they have a relapse, it's a full-time job.*

Families affected by pediatric MS were not immune to other stresses. Several families we studied had experienced recent deaths in the families, job losses and other illnesses. Some families had other family members with MS and some youths had other health problems. Adding the stress of pediatric MS on top of other stressors placed some families at special risk.

One family reacted to the pediatric MS somewhat philosophically because it was one in a long line of crises they had endured, and the mother spoke confidently of the family's ability to handle crises because of all their previous experience: *"This is just one more thing on the plate, I guess."*

The stress had a variety of effects on parents' lives. One problem could be sleep. Here are two mothers' experiences:

*[14]: In the first couple of months I'd wake up in the middle of the night, three in the morning, and start researching or get an idea or, "Okay, maybe it's this, maybe it's that."*

*[16]: I don't think I've slept a solid night since he's been diagnosed... When your son has seizures in the middle of the night, you tend not to sleep great after.*

Another issue was employment. Most parents reported that their employers were supportive and flexible and their child's illness did not affect their work or their job, but sometimes the parent's need to make their child's care a priority had negative effects on employment. One mother lost multiple jobs after her son was diagnosed because of the amount of time she needed to take off, and another was terminated two weeks before the company would have had to meet legal obligations through the Family Medical Leave Act. She described what happened as follows:

*They [her employers] said, "You've called out six times in the last eight weeks." What are you going to do? You got a sick kid and every single time I called out, there was a doctor's note. What are you going to do? He comes first.*

Other mothers were not able to seek a job because of MS. Another mother said:

*...thank God I was unemployed, because I would have never been able to work his first year-and-a-half. We were down here [the hospital] every other week with something...first of all, I stayed here with him for ten days, and we were back again three weeks later for three days. Then we're back again...I would have had to quit my job. Maybe they would have accommodated me, but I highly doubt it... So that's been difficult. Financially, yeah... I am [working now], which is still difficult, because coordinating – it comes in spurts of the coordinating [medical care and services].*

In other cases, parents' jobs were not at risk but they lost income because of missing work. Even on the job, the stress of MS could affect job performance, as one father explained:

*It was hard because I'd be operating machinery and I'd find myself wandering-- like my mind thinking about it. ... That's my job, so it's kind of-- not really safe to be thinking.*

Pediatric MS could also put stress on the parents' marriage as well. The vast majority of our interviewees were mothers, and it is clear that pediatric MS often places a significant burden on them. Sometimes it could be hard on marriages if mothers were taking on a disproportionate share of the responsibility of managing the illness. There could be resentment if fathers were not as attuned to the symptoms of MS or the youth's specific needs. One mother talked about her husband wanting to believe that the diagnosis was mistaken and their son was not ill. The attention to the youth that was required could make it difficult for spouses to pay attention to each other. If parents were separated or divorced, the MS could strain already difficult relationships between the parents, or a sensitive and supportive response of both parents to their ill child could actually ease tensions.

### **Effect on Siblings**

The MS could be hard on the youth's siblings as well. One normally reticent daughter broke down one day and told her mother, *"Oh, my god, I thought [Name] was going to die."* That same sibling wrote her college application essay describing the family's experience with pediatric MS. Some siblings worried that they would contract MS as well. Others simply wondered why their sibling got MS and they did not; as one mother put it, *"the randomization of it."* Sometimes siblings felt frustrated or jealous about all the attention to the youth and the illness. One mother quoted her non-affected daughter as saying *"Mom, everything is the MS, everything."*

## Positive Impact

We asked if MS had had any positive effects on the family, and most parents could identify ways in which the family's response to MS had been constructive. Many parents said it brought the family closer together, sometimes leading some of its members who were disconnected to focus more on the family. Some married couples became closer because of going through the illness together. One mother credited the family's response to MS as a factor in keeping her husband and her together. One single mother talked about how her son's father, who had disappointed him repeatedly over the years, was being attentive and engaged in his treatment and contributing more financially. One mother said that through MS the family has "*learn[ed] how to have more empathy with other people,*" and another mother reported that the youth and her brother are "*butting heads*" less because the illness has made him more sympathetic. The idea that "*at any given moment, things could change*" made them value family relationships in the moment. It helped parents get their priorities straight, one mother reported, saying, "*it's made me realize, okay, cleaning the house is not important.*" Another mother described it this way:

*It's also made me figure out what's important. Petty stuff, not into it. Getting done what I need to get done with him, that makes the difference. Making sure he's okay, making sure that Friday nights when you're taking the injections and I know he's going to feel like crap, I've made-- I've put on fresh sheets on the bed, the pillows are plumped and he is comfortable and he's at his best. Those are the things that have changed, you know. The changes are elastic waist pants now because he's comfortable in them, you know? Those little changes that you don't really see until you're in the throes of this that you're like, "Okay, whatever. We'll just do it. It is what it is now."*

More than one parent talked about how they had gained added respect from their children for the hard work they have done because of the MS, and the sacrifices they have made. One said about her son, *“I find he actually talks to me more about things, and he’s very brutally honest.”* Two parents talked about how the MS had led their daughters to communicate more with them.

### **Communicating about MS**

An adaptive response to pediatric MS demands coordination among family members, and requires family members to communicate effectively about the illness. This can pose a substantial challenge, as most of the youths in the sample were in adolescence, a period of life in which communication between parents and their children can be problematic.

The amount families communicated about pediatric MS depended a great deal on the daily impact it was having on their lives. Increased communication was required during times in which youths were symptomatic. Diagnostic procedures had to be completed, complicated treatment decisions had to be made, and families had to communicate with the outside world. When adapting to the impact of the illness was necessary, and youths and parents had to learn how to administer medications and work together on treatment, MS could be a constant topic. On the other hand, once the process of diagnosis was completed, the family and health care providers had developed a treatment and monitoring routine, and the family had made whatever adaptations were needed, families often did not feel a need to discuss it. One mother said that she

sometimes forgets that her daughter has MS, because there has not been another attack since the first and she is living a normal life.

Youths who had endured acute episodes and had devoted many hours to dealing with the illness were simply tired of talking about it. Another mother explained:

*We don't really talk about it. I mean there is no reason to bring it up. I mean we don't hide from it either, but I mean it's not like we just start having conversations about it. I mean we've discussed it a couple times, "Well, have you done your shot?" "She takes it on Friday and we'll be all set." ...We don't hide from it. We just don't talk about it. It's just, I mean we just treat it normal, but...*

Even though a number of families no longer talked about MS frequently, it was always in the background, as one mother explained, *"We don't talk about it every day. But we know it's there."*

Processing information about MS could be emotionally difficult. In one family, the mother was the family member who read the pamphlets and other readings about the illness. The father depended on her or the neurologist to process that information, as he described:

*I'm going to tell you the truth. The less I know, the better. Like, I don't want to know all these details about MS and all this stuff. I don't want to know it. I know I'm going to have to deal with it. But in my mind I think it's the less I know, the better. I know she possibly has it, I know we're going to go do the treatments. I don't want to hear a bunch of mumbo jumbo-- a bunch of-- tell me all these facts and all this stuff. I don't want to hear that. I'm sorry if it sounds rude. I don't care. I'm an adult, I'm going to be here for my daughter. When I go to the doctor's, I'm not rude to them. I listen to what they say. That's where I find out my stuff. I got frustrated...I want her on the medicine, she wants to be on the medicine. We'll deal with it. It's the wrong attitude to have sometimes, I understand.*

The nuclear family also needed to communicate with the extended family about the illness. Generally, parents and youths received considerable support from family members, and their communication with them about the illness increased the assistance and emotional comfort extended family members could provide. On the other hand, it was difficult for parents to explain a very complicated illness to extended family members who had questions and understood less. Some extended family members made negative comments which were difficult for parents. One mother said, "*Nobody knows what MS is, so trying to explain it, it's hard.*", and another said, "*I didn't want to confuse anybody more, I'm confused myself.*" Sometimes parents had to deal with the pessimistic family members. In the words of one parent;

*Everybody gets nervous because they all see-- they've seen other people with this and always it's always at a worst state where they're basically wheelchair bound or they're having a lot of issues, motor skills aspect, and that's where they start focusing and they get nervous on that stuff there.*

Talking to extended family sometimes involving some judgments about what others wanted to know and needed to know:

*I do remember now trying to tell them. Because we had the booklet there, and I said, "This is what [Name] has. How much do you want to know?" Most of them didn't want to know a whole lot. And I said, "You do need to know a few things." And I said, "But it is an autoimmune disease. And her body is attacking her CNS and her spinal cord. So anything that attacks is what type of symptom that she will have." I didn't go into what I knew about it, just that whatever area it will attack is-- so if it affects her arm, then that was the area that was affected. And that's all they wanted to know.*

One big concern is whether reticent teen-agers will tell parents and other family members when they are experiencing symptoms. As one mother reported, "*...her older sister told me, 'She tells me everything, and she didn't tell me when she was starting to have problems'.*" MS symptoms can often not be seen, but young people may not want to

admit to themselves and/or others the onset of symptoms or have to go back to the hospital or change treatment. Many parents were worried about missing symptoms in this way and implored their children to report symptoms regardless of their situation.

### **Parenting the Young Person with Pediatric MS**

Pediatric Multiple Sclerosis places additional demands on mothers and fathers. Parents have to re-think a host of parenting decisions when faced with an illness that suddenly renders their increasingly independent adolescent children dependent, makes substantial demands on youths' behavior that parents have to oversee, and sometimes leads to emotional and behavioral challenges that parents have to respond to. It is not surprising that several parents reported that pediatric MS changed the way they parented. Yet many parents felt that they had established a solid base in how they parented before the MS that the illness did not alter.

One challenge parents had to deal with is how stress related to MS could contribute to conflict within the family, as one family described:

*It was a little difficult because we were all sort of walking on eggshells, like looking to see who was going to point the finger at who and blame who first. And then after a while, it was like, "You know what? No one's blaming anyone. Let's just do this thing. Let's all do this together. Let's get on board and let's try to get healthy."*

One parenting issue was setting reasonable expectations given what the youth could and could not do. This was often hard to determine, and parents many times differed between themselves, as one mother explained;

*My husband's more hard core, like I think I tend to be like, "Well, if she knows her body. If she's tired." And he's more or less like, you know, "I think she's lazy." Well she is lazy, but I think part of it-- I've always said to*

*her, and the doctor said the same thing, you know, "If you feel tired, if your body's tired, rest. Your body needs to rest." So she can push herself to a certain degree, but then I think she pushes herself so much that she does get tired. You know, it's really hard. Like, and that's the hard part, is how much of it is normal teenage stuff and how much of it is the medication and the diagnosis and the disease itself? And you don't-- it's hard to see the difference.*

Parents described the challenges of determining the degree of independence that their children with MS should have. Sometimes parents intervened to limit their children's independence if they thought youths were at risk because of the MS, more than they would have done without the illness. One factor was the perception that disease-modifying treatments suppress the immune system, placing children at greater risk of contracting a communicable illness. Sometimes this got to the point that parents ruefully admitted to being overbearing. Youths often chafed at the limitations on their independence, and families had to work out a solution. One mother described it in this way:

*I still love her sense of independence, but now sometimes, and I encourage her to try hard, but sometimes she wants to take it upon herself, "I can walk down the stairs." I'm like, "You know, it's okay to need help and it's okay to accept help. It's important to know when you need help. And nobody made it through life by themselves." So I try to be more-- what's the word I'm looking for-- more attentive. She doesn't like that. She feels like I'm babying her when I'm being more attentive, because she is used to her sense of independence.*

Faced with a reticent teen-ager reluctant to communicate about symptoms, vigilance in parenting could be justified. Witness these mothers' experience:

*When I notice things are off, I'm like, "Are you all right, are you all right?" "Oh, my God, would you stop asking?" Because I know him. I look at him, I say, "Because I know you, you wait three weeks and then you go, 'oh, by the way.'" I go, "And then when we get here, you'll say to [the physician], 'Oh, yeah, I've been feeling like this for like two weeks, I just didn't tell my mom.... And [MD] is just looking at him, he's looking at me. She's like, "[Name], I see all types of parents come in here. This is the*

*kind of parent you want. You might find her nagging you. You might find that she's a pain. You might find that your mother's overbearing and she's very bossy. That's what you want."*

*I get nervous if she's not going to say a certain way she's feeling. Like if a flare-up is coming, that I can't visually see, because a lot of times you can't visually see MS. And I get nervous she's not going to tell me in time where we can hopefully avoid possible lesions or something... we have to keep reinforcing that. If you feel different, tell us. You got to tell us. This is the only way to fight this whole multiple sclerosis thing... Tell us, "Hey, I'm feeling a little weird," and [MD] said call any time.*

Sometimes youngsters advocated for greater independence in spending time with friends, engaging in activities and making their own decisions about treatment. Other times parents started to place greater expectations on youths to manage their illness. One mother talked about initially "babying" her daughter, but then having to switch to encouraging her daughter to be more independent because the young person was hesitating to live her life fully because of her preoccupation with being sick. Sometimes parents felt they had to intervene with grandparents or other extended family to maintain the most appropriate expectations for their children, as one mother illustrates:

*She can say, "I have a headache," and Grandma is, "Oh, what's wrong with you-- what's wrong with--" "I'm like, "No, no, no, no, she's fine."*

Several parents talked about how the illness had made them more vigilant parents. This could cause them to monitor their children more closely than parents not dealing with MS would, and some parents recognized that they had become overbearing as a result. Parents and children needed to negotiate a way to handle this, as one mother explained:

*Of course, I was asking her too often how she was doing, "How are you feeling? Any episodes?" And she was kind of rolling her eyes at me and getting a little mad. And I said, "Okay, I won't ask you as long as you promise to tell me if you are having some sort of effects or symptoms that you think are odd or weird." So that's how we've kind of left it. I do, if I*

*notice that she's sleeping more, if she's getting headaches more, I do ask her. But I try not to harp on it.*

Another risk was that parents could be so over-protective that it was difficult for their children to live their lives, as one mother and father explained:

*I didn't want her to do her chores, I didn't want her to shovel, I didn't want her to-- nothing. You just sit in the house in a bubble. Put you in a bubble. She liked that a little bit, I think: [not having to do] the chores and the shoveling. But then... she couldn't do her dancing and exercising... But she's back to normal... Well, we all are because I got a reality check.*

Sometimes the two parents or even extended family differed in the degree to which they allowed or expected their children to be independent and self-sufficient. One father talked about it in this way:

*I think truly my ex-wife kind of babies him somewhat, but, you know, almost spoon-feeds him when it comes to a lot of stuff.*

Some parents talked about being somewhat more indulgent with their child since the MS.

Some felt comfortable with this and some did not. One mother put it this way:

*I was kind of getting down on myself thinking maybe I was a little bit too easy on her, and now I have decided...I am going to spoil her a little bit. It's okay, nothing wrong with it. So, it has changed in that way, but I'm comfortable with it.*

Several parents mentioned paying greater attention to healthy eating, organic food, exercise, and other healthy behaviors as a way of combatting MS. One set of grandparents made this their mission:

*He wakes up in the morning and my dad gives him fresh squeezed vegetables and oranges at least three times a week, and the other three times a week he switches between eggs, but everything is organic, everything is homemade. Soup, he takes bean soups of every different kind, he doesn't repeat food at least another three days a week. They completely switched the food for him.*

One mother instructed her daughter that her future prognosis depended on her behavior in maintaining a healthy life style as well as taking her medication. Sometimes the emphasis on healthy eating caused friction as children and other family members may not have wanted to have their diet constrained.

Parents also had a number of concerns about environmental factors that might be related to MS. One parent had her water system lead level tested, and switched the family from drinking tap water to bottled water. Families have taken steps to remove environmental irritants from youths' rooms and added vitamins and supplements thought to be healing. The following passage illustrates the inner search for a cause some parents experienced:

*What caused it, we don't know where it is. Is it in the house, is it outside?*

*What happened? Is it the flu shot, is it something else?*

### **Impact of MS at the Time of the Interview**

Despite its often overwhelming initial impact, most families in our study were past the initial stage of the illness, had adapted and benefitted from treatment, and were doing well. Most youth discussed in the study were on disease-modifying treatment and symptoms were usually either absent or not having a severe effect. However, some young people were still struggling with symptoms at the time of interview, either because the MS was still relatively or an effective treatment has not yet been found. Chapter 7 details the ways in which youths and their families adapted to the illness and the resilience they demonstrated over time.

## Summary

Pediatric Multiple Sclerosis can have a significant physical impact on the well-being of affected youths and an overwhelming emotional impact on the whole family. Youths experienced feelings of fearfulness, frustration, embarrassment, self-consciousness, irritability, and anger. Youth with MS worried about the effects of MS on their school life and their relationships with peers. But some parents talked about how resilient their children were and how little emotional impact they felt the MS had on them. Parents had constant anxiety about the possibilities of symptoms, relapses and progression in the disease, and sometimes had feelings of responsibility for the illness. Parents were reluctant to show their emotions out of fear of further stressing their child. Managing the illness and its treatment were enormously stressful for parents, given everything that had to be done and all the emotional stresses they endured. While most employers were supportive, some parents lost jobs or could not work because of the demands of the illness. Pediatric MS was sometimes a stress on parents' marriage. But the illness could have a positive impact, by bringing parents and the whole family closer together, re-setting their priorities, and increasing parents and children's respect for each other. Some families did not talk about the MS much if the child was not symptomatic, and some children were reticent about discussing the illness. How they communicated with others about the disease varied, but families were usually selective about disclosure. The illness often affected parenting, sometimes increasing parents' vigilance about healthy life styles, sometimes causing parents to be over-protective, and usually complicating family negotiations around the independence of the adolescent with MS. The impact

described was largely retrospective and most youths and families had adapted well by the time of the interview, as discussed in Chapter 7.

## Chapter 5

### Treatment

*“I respect that you don’t want to, but you’re still 14 and I’m your mom and we’re going to do this, so we’re doing it.”*

All of the youths in these families were receiving disease-modifying medication except for one who was about to begin treatment at the time of the interview. Most youths were either experiencing no symptoms or their symptoms had limited impact at the time of the interview, though those youths who were struggling with symptoms at the time of the interview are of course cause for concern. While assessing the impact of disease-modifying treatments is beyond the scope of this study, most families were maintaining disease-modifying treatment and their decision appears justified.

Several youths tried several different medications before they found one that appeared to be effective, and had side effects that young people with MS could bear. The difficulties associated with disease-modifying medication could be very hard for youths and families, particularly when using an injectable medication. The trial and error involved in finding the right treatment was difficult in itself.

#### **Making Treatment Decisions**

The children, their families and their neurologists usually worked together to make treatment decisions. Families were typically guided by neurologists’ judgments, and generally reported that their health care providers helped them make decisions. Usually the physicians offered ample information, described choices clearly, and took seriously children’s and parents’ thoughts and feelings when making recommendations. Most families reported that their neurologists were good at communicating with them and

answering their questions throughout the process. Sometimes the communication and decision-making process occurred mainly between the young person and the doctor. Here is one parent's account:

*And he's [her son] so funny; he's like, "Well, no on that one, no on that one." Because she listed the side effects, like the top side effects. And so we kind of had it narrowed down to two. And then he looked at [the physician] and he said, "So, if I was your son, which one would you pick?" ...He's like, "I'm serious." [The physician] is like, "I'd probably go with [injectable DMT]." He's like, "All right, let's try the [injectable DMT] ...I can call [the neurologist. I can email and she responds immediately. Always. [The neurologist will] talk to [Name]. I'll say, "You know what? I think you just need to talk to him. Here are the symptoms from him." [The neurologist] is like, "Yeah, put him on the phone." Everybody here is always very accommodating. We're very thankful, very lucky.*

One family praised their neurologist for being particularly good at facilitating decision-making by the family, withholding recommendations until the family had made a preliminary decision and then reporting that their choice echoed what the neurologist would have recommended. Other members of the treatment team received praise as well. One was a therapist who helped families sort through their thinking about treatment. Another was a child advocate who counseled the doctors and nurse to be aware of the young person's distress, which was making it difficult for her to understand what treatment providers were communicating.

Neurologists played a very large role in treatment decisions. Some parents chose to be very actively involved in the decision-making process, while other parents were content to look to their doctors' recommendations and follow them. All parents took their children's opinions and feelings seriously and in some way involved them in treatment

decision-making. Some parents of teen-agers said they left the final decision in the youths' hands; most made the final decisions themselves but took their children's wishes seriously. Here is an example:

*So I sat down with [her daughter] and she mostly made the decision, kind of based on how frequently she would have to take the shots and that sort of stuff. And a couple of times she was kind of like, "Well, what if I don't want to do this?" And I said, "Well, I respect that you don't want to, but you're still 14 and I'm your mom and we're going to do this, so we're doing it." And she was like, "You're right. You're right." ...there is a balance, but I try to let her play a role in it.*

The research literature influenced decision-making as well. Several families mentioned instances in which their neurologist discussed research findings as a factor in their recommendations. Many families also did their own reading and Internet searches to inform their decision-making. However, research did not always provide clear answers and its usefulness was limited because trials of DMTs in the pediatric population are only just beginning. As one family explained:

*I think that we kind of go back and forth [on treatment decisions] based on research, it's all based on research. So, I want to know what the research shows. But it's hard because...less than 5 percent of kids are diagnosed under the age of 21. So, we had that kind of working against us because we weren't sure if these treatments and therapies that they have in place for people that are older are going to work on her. So that was kind of scary, like reading about different medications and which ones might work.*

One parent expressed concern about whether treatments developed with Europeans and European-Americans would be effective for her African-American son. She talked about genetic differences related to race that would mean that standard treatments might be less effective for children of color. She felt that health care providers

were not taking the professional risks necessary to explore differences in treatment response between different racial groups.

The unknowns around starting treatment were difficult for parents. As one parent put it, “*You don’t know what effect this medication is going to have on my child.*” One factor making it difficult was parents’ worry about serious side effects. Several mothers described the difficult choices they made:

*And it’s hard to, even with what she is on now, she is on the [DMT] and even though there is only one major side effect that could possibly happen, the potential, it’s like signing your soul away to the devil. You just don’t know. If she comes in contact with this JC virus you have no way of curing her of this brain disease that she could get. You have no way of curing her of the disease that she currently has and you’re giving her medications that are going to give her more problems in the long run... Now the [DMT] is not really working and they want to, they’re talking about chemotherapy. You want me to put my 13 year old daughter on chemotherapy and then essentially possibly make her lose the ability to have children in the long run? My daughter loves kids. She is begging me to have another kid right now. And I don’t want to bring another person into this messed up world, this messed up world where these doctors give you all sorts of shit and they don’t know what it is going to do to you.*

*We were debating on doing steroids. My mother had just passed away, like nine months before that and she was on steroids. Big doses of steroids. And it made her diabetic. So we were hesitant on doing that. And as it turned out, she still had some residual issues with her hand being numb and her feet being numb. So we ended up doing steroids in July. And [Name] didn't have any issues with it.*

Parents discussed with their children the potential impact of side effects on their life:

*And we were still on the fence with the pill, the [DMT]. Because I said to [Name], "You know, what if you have diarrhea in the middle of school? What if you throw up? These are things you need to think about."*

### **Treating Symptoms with Steroids**

Since most youths first sought help because of an acute episode, IV methylprednisolone (IVMP) was often the first treatment youths received. For many it

was effective in shortening the flare-up, but it did not work for every youth and every symptom. Moreover, the side effects of the steroid treatment were sometimes difficult for the young people with MS and their families. A number of parents described the temporary mood changes which occurred during treatment with IVMP. One parent put it vividly:

*Have you ever taken prednisone? Okay, you know it makes you come out of your skin? What do you take, like 40 milligrams or 16, you taper down, and you're cranky then. This is 1000. And I was telling my sister. She's like, "Honey, you know how I get all itchy when I'm on my prednisone?" I said, "Yeah." She goes, "I'm only taking 60 milligrams. They're giving your son 1000." I go, "Oh, my god." She's like, "No wonder he's behaving the way he's behaving." I'm like, "Okay, this is making sense now." Yeah, he was not a very nice boy to his mother. He started whipping a towel at me.*

Relapses were often treated with IV methylprednisolone. Youths who had to try several medications before finding the right one or were still searching for the right treatment were sometimes treated with IVMP several times.

### **Difficulties with Injections**

The biggest challenge that parents reported with treatment was the difficulty of injections. Usually the first medication that doctors recommended and that families tried was in the form of a subcutaneous or intramuscular injection administered by parents or by young people with MS themselves. As one parent explained:

*And unfortunately, the research wasn't there for them, for safety reasons the FDA didn't have anyone younger than 18 on an oral pill. So, he said right away we couldn't do that because he didn't know if it was safe for her to do it.*

While some parents reported that the child and family had little difficulty with injections, other parents reported that administering injections was very difficult. Youths

experienced pain, burning, and other ill effects from the injections, and parents felt a great deal of distress watching their children receive the injections. In several cases, the difficulties with injections disrupted the treatment or were a major factor in causing families to stop or switch medications. Auto-inject devices were generally helpful, but did not eliminate the problem, and one youth found the auto-injector more painful than the injections administered by hand. Difficulties with injections are not unique to youths with MS: research has shown that as many as 40% of adults with MS discontinue injectable therapies within five years.<sup>20-22</sup>

*We're right now on the third different drug. We've gone through two sessions of injections which broke my heart to even have to do it to him and then he started doing it to himself and I don't know if I could do that on a daily basis and do it twice-- do it daily where if you do that to yourself and those areas swell, and you can see it's painful, I give him a lot of credit... Then when we went to the next protocol on the injections, were not as good. What I mean is that pain level, because they would tell you that my son's about 145 pounds soaking wet and he's a bone rack. And all of a sudden you're taking an injection and you're watching the arm because you rotate arm/arm/leg/leg, those areas would swell right away from the injections where basically we had a good system where he would do it, ice pack it down, go sit-- you could see in his face that it was painful and he was hurting with it and that broke my heart. But yeah, he deals with it better than I could when it comes to it.*

One problem with the injections was pain at the injection site: One mother admitted that “we threw one away because she was in pain. I mean, she couldn't take it anymore. Toward the end, it was so painful.” A second problem was the numerous welts, bruises, and scarring that sometimes occur after repeated injections (One mother said, “Oh, my God. She got bruised everywhere!”). One parent described the development of scar tissue, the difficulties it posed, and her distress that she was not forewarned:

*And then after so many months, what ends up happening is you develop scar tissue and that's one of the things that they don't tell you. That's the*

*part that-- actually, that was probably something that they should have told me that they didn't. That's one of the things that I didn't think about it then, but now-- yeah, you build up scar tissue in your legs and then there's less and less places that have fresh skin that you can inject that's not going to hurt. So you got to think about you're building up scar tissue and you're injecting yourself through the scar tissue to get into the muscle and it's very painful.*

Regular blood tests were also part of the treatment protocol. Blood draws were often experienced as difficult by the children.

*And the fourth time somebody stuck him with a needle---I'd never seen my son get really angry. He screamed at them and said, "Everybody out. You're done, you're not touching me." And I don't blame him. I'd have been a little cranky about it, too. And they brought in an anesthesiologist with an ultrasound machine. The guy was awesome, cool, calm and collected. And Ian looked him dead in the eye and said, "You got one try before I'm out," and he did it.*

A third problem was the flu-like side effects of the interferon beta injectable medication. Two youngsters were at times unable to go to school after injections because of the side effects and had to stay in bed. One girl became short of breath and lost consciousness after an injection of her DMT; although it is not clear how this was related to the medication, it contributed to the family's wariness of the medication. One parent described their post-injection experience as follows:

*I think there was some days when she would end up with like the chills. And it would be so bad, like we went away last summer and she basically her legs were-- her body, her entire body, she could walk, her balance wasn't off. But it was right after we had done an injection and her legs were ice cold. And she just could not get warm and it was just devastating.*

A fourth problem was the anxiety several children and families felt about needles and giving injections, as several parents explained:

*Well, treatment was hard because it was the injections. She's afraid of needles, I'm afraid of needles. Guess who had to do the needles?... Thank God they get the auto inject, so I did it with the auto-- well, she did it with*

*the auto inject. I got used to do it without it because it hurt less, I guess. But yeah, I didn't like it. But then she waited and we waited and we heard about the pill coming out and waited so she finally got the pill. So that was nice. So she's been on the pill for almost a year now.*

*Every time I see infusion, injections, it's like my heart breaks. She doesn't feel it, and she says it doesn't hurt, that she's fine. But I tell her, "You're not a mother so you don't know how it feels." ...It's like it hurts her, it's hurting me. She says it doesn't hurt, but my heart doesn't believe that. My heart says it's hurting her, that she suffers.*

*It's just barbaric, having to stab yourself...Thinking about injecting her intramuscularly or under-- just under the skin. I mean, it was just-- it was kind of really overwhelming.*

Families did typically overcome the anxiety; in the following case example, the young person with MS was actually calmer than her mother and successfully pushed her to overcome her emotional reaction:

*The first time I did it, I literally thought I was going to throw up because it was just the sensation of sticking a needle in my child that I was like, "Woo, woo, woo." But [her daughter] told me, "It's my body, Mom, suck it up." She's like, "You're not getting the shot, I'm getting the shot. Could you just suck it up and give me the shot?" And so it's three times a week, it's routine. It's just part of what we do and, you know-- at the beginning, it took a long time, it was like a 45-minute process of mentally getting ready, warming it up, doing the shot, doing an ice pack afterwards. And now she's just like, "Let's just do it." Bing, bang, boom, done. Twenty minutes, it's all done.*

A fifth problem was that the injections made it more difficult for the young person's ability to maintain privacy about the illness. Related to this was the self-consciousness or embarrassment youths would feel over receiving so visible and tangibly invasive form of treatment. As one parent explained when she was discussing the advantages of oral medication over injections:

*[The pills are] a lot easier to deal with. Traveling, having a pill bottle compared to having-- to have to deal with vials, with syringes, or going through airports and all that. Even though with documentation, still people-- especially being a kid. You don't need extra eyes looking at you*

*thinking you've done something wrong. Or, why does this person have this? What is wrong with him type situation. And he's done much better going to the pills in that aspect of it there.*

Visible welts and bruises expose the reality of MS to the world, as one mother explained:

*She always had those welts just everywhere she went. So sometimes, kids always ask what it was. She always had to hide her legs and her arms, her belly. And it would stay forever because if they weren't red, they were like bruised, like a purplish discoloration.*

A sixth issue was whether particular injectable medications were indicated in pediatric cases. One mother read information that suggested to her that the injectable medication her daughter was prescribed was not recommended for children and adolescents and worried about an “immune reaction.”

Sometimes the mother administered the injection, sometimes the father, sometimes the young person with MS, and sometimes a combination of family members. Often fear of needles influenced this decision. In one family, the father gave the injections because the mother was too afraid. One daughter was too frightened to give herself shots and wanted her mother to do them; the mother pointed out the limitations of this when the daughter wanted to go to a sleepover, and the daughter overcame her fear and learned to do the injections on some parts of her body. One daughter started the medication regimen by injecting herself but then asked her mother to take over after one particularly bloody injection. Another daughter overcame her own fear of needles and gave herself injections to spare her mother having to do it. Sometimes it was a developmental process in which the youths gradually became ready to inject themselves as they became older and more mature.

*And it came out of one of these sessions with [MD] when we were probably, I don't know, six months or a year into this-- the last sort of shots that we were going through and that, "Well, how are you doing with the injection?" And I said, "He's never given it to himself, we do it." And I don't know if something transpired between him and my ex-wife because the next thing when he came to my house that next weekend, he was doing the shots. And I was like, "You sure?" He goes, "Yeah, I can do it." I said, "Okay." And from that point there, he would do it. I mean, I would try to clean up, take care of the needle after because I knew he was in pain and he was with the ice, so would clean up the needles, put it in the needle container box and all that. At that point there, and he did it for probably the last six to eight months before they swapped him over to the pills that he's on now.*

One mother insisted her son do the injections himself:

*It's his body, his life. I'm not going to go with him to college to do his injections, he's got to do it. He chose it, he needs to follow through.*

Sometimes youths would procrastinate taking the medication or skip days, and there was often a question about how much families could stray from the treatment regimen because of other life demands yet still have a good treatment response. Often who gave the injection and whether or not it took place got was the subject of an adolescent-parent struggle:

*I think that she [young person with MS] wanted to do it [the injection], but then felt like she knew it was going to hurt or that she wasn't sure if it was going to hurt, so she couldn't do it. So, there was one night in particular, she wanted to do it. She insisted that she was going to do it. She went out, she was doing it-- we were doing it on a Friday and then she wanted to switch it and do it on a Saturday because she wanted to go out with her friends on a Friday. So I'm like, "All right, I'll give you that." So we switched the nights. She was supposed to do the medication. Two hours, two hours, she was out. I'll never forget it. She came home at 11:30. I'm like, "Okay, it's time for your medicine." "All right, I'm going to do it." And I was just so frustrated I said, "Fine." I said, "You're not going to let me do it?" She's like, "At this point it's going to hurt. I don't want you to do it. I'm sick of doing this." So we kind of battled back and forth. You know, it's kind of like that struggle...I think that part of it is the toughest part when you're a teenager.*

Several youths and their families switched from the injectable medication to an oral DMT. Sometimes this was because a DMT was not sufficiently effective but more typically it was due to poor adherence with the injectable medication. One youth told his parents he was giving himself injections but then they found unused vials in his room. His mother decided she had to watch him take his medication from that point forward. Even when youths continued with injections, procrastinating, and skipping injections was sometimes an issue. One mother explained in this way:

*It's still kind of tough. The shots, they hurt and they kind of-- She always tries to bargain what time of day we're going to do them based on what she has to do, and, "Well if we wait until tomorrow" and that sort of stuff, so it's still tough. It's still tough.*

In two cases, adolescents with MS refused to submit to further injections, against both their doctor's and their parents' wishes. In both cases, guided both by empathy and the practical need to proceed with some form of treatment, the adults finally gave in to the child's choices, which became a factor in switching to oral medication.

Three oral medications have become available in the United States, and clinical trials with a pediatric population have begun. Oral medications became a new option at least for the older adolescents, and several youths in our sample were pleased to have recently switched from injectable medication to one of the oral forms of disease modifying medication. One mother felt added satisfaction that, by participating in a clinical trial, her family was potentially helping other children with MS. Other families were reluctant to join a clinical trial because of the possibility of receiving a placebo if one were assigned to the control group. One parent had done her own research on the use of an oral DMT in Europe and advocated for her daughter to receive it.

The following passage illustrates several challenges and ambiguities surrounding decision-making about treatment in these cases and the interplay among children, parents and neurologists in making these decisions:

*What's the risks if we switch to a pill?" Because she was adamant. "I don't want to do the injections anymore." ...So I was more concerned with, "Oh my God, we switch it. Then we run the risk of this medication not working entirely." And then we find out the [injectable DMT] actually worked better than the pill. So there's a risk. You don't really know. So, she wanted to switch so it was her wish and that's what we ended up doing. And [MD] thought it was the right time because she was at that age where she was, you know, almost 18 and [the doctor] thought that some of the-- after being on it for a year, [the doctor] thought it would be a good idea to switch to the pill. And then there were risks with that. And so far, she's done really well and hasn't had the side effects that she had with the injector pens. So we've been very fortunate so far ... And the unknown is you don't know what's happening inside. So you take a risk.*

### **Trial and Error**

Finding the right medication was often a process of trial and error. Several youths had tried as many three or four different medications over a period of months to years. As one mother said, "every time the medicine doesn't work and we have to decide what new medicine is for us it's hard." The experience could be gruelingly repetitive. After presenting initially with disabling symptoms, youths were treated with steroids with all their disturbing side effects, and then received a disease-modifying treatment. DMTs took weeks to months to try and adapt to. Parents were vigilant about watching for signs of both the illness and reactions to the treatment; one parent described calling the hospital with new reactions to a DMT and figuring out with the hospital that her daughter simply had a common viral illness.

Disease-modifying medication prevented some of the exacerbations of MS, but not all. Sometimes a DMT would be effective for a period of months or even years and

then, for no apparent reason, it no longer prevents MRI activity or exacerbation. Another DMT would be tried with no certainty of success and with the possibility of repeating the difficult cycle again. Each time, as one parent put it, “It's like the beginning, all over.”

Here is how two parents elaborated on the trial and error process:

*You know, they really can't give a prognosis because they don't know. And like I said earlier, I believe it's more of-- it's trial and error and I still believe to this day that's how-- when it comes to these different things, that's how they have to react. They'll do tests which confirms different diagnosis. But when it comes to a lot of that there, it's still trial and error.*

*Her father was at first, “Oh, my daughter's not a guinea pig.” It's like, “Well, we don't know what's going to work for her”... I know she's not a guinea pig and I know you guys aren't trying to make her a guinea pig. It's just we've got to find out what works, you know? We can't just say, “Oh, that's the best one,” no. Because look at, the one that she first said, “Oh, everybody works good with, it's been good,” they don't work good for her. But I'm glad that that part of it is over. The part, finding out what's going to work for her, because that was hard to deal with. You know, the relapses and being in the hospital for those five days. I had to leave my other kids. Their father's always been there, but you know, mom's not home.*

Caution regarding the oral medications played a role in the trial and error process.

Parents in some cases reported that neurologists chose not to prescribe oral medication at first, because they were new and had not been sufficiently tested in children. Several young people with MS did eventually receive oral medication after first receiving injectable or infused DMTs. In some cases, the change to oral medication was made because injection and/or infusions were ineffective in managing the disease. In other cases, the neurologist decided to prescribe oral medication after youths and/or their families refused to continue with injections. Thus, to some degree, the trial and error process was predictable given that a) Physicians first prescribed injectable medication given its history of use in a pediatric population, b) A number of youths and their families

eventually could not tolerate injections, and c) Physicians were then willing to prescribe oral medication when children and families refused to continue with injections and/or infusions.

For some families, expense was an issue if they did not have medical insurance that paid for a diagnostic procedure or a medication. One parent praised the hospital social worker in helping them get free medication from a pharmaceutical company, but also noted that this limited their choice, as they could not readily switch from one medication to another. Indeed, this meant they had to rely on injections rather than oral medication – fortunately this youth did well with injections, unlike many others.

### **The Importance of MRIs**

One important component of managing Multiple Sclerosis is the use of magnetic resonance imaging (MRI) to monitor the development of inflammatory lesions in the brain and spinal cord. Management of MS involved regular MRIs to track the status of the disease over time. The MRIs become important events, and families would worry that the MRI would indicate that the disease was worsening even in the absence of symptoms. MRI results are an important factor in making treatment decisions, so the report from the MRI became a time of hope and fear:

*Each time we switch medicine, it just new lesions on her brain comes out. I guess the doctor doesn't want to see that. He's concerned, so he wants to switch the medicine all the time because for her good, you know.*

*The Fall's coming, we're going to have to go get another MRI. And to get those results is scary. You hope that the medication that when you make a switch, there's a risk, you know? She's done really well transitioning with medications and stuff, but you just don't know, you know?*

## Treatment Adherence

In the absence of inflammatory attacks, most of the young people with MS showed few observable signs of the illness. It is understandable then, that families may have been tempted to forego treatment during these periods, particularly when they understand that both the course of the illness and the response to treatment are so unpredictable, and youths may continue to experience side effects of medication. One mother who did *not* discontinue treatment explained the temptation to do so:

*And it's hard to look at her and know that she has MS because she looks perfectly healthy. So it's hard to rationalize giving your child this shot when outwardly it doesn't look like there's anything wrong with her.*

Young people with MS and their families may question the need to continue treatment, and may decide to discontinue it. This did not happen often in our sample, but it did happen. One mother explained:

*...they did some tests. It came out that nothing new came up in her brain. So what happened was that I decided not to give the medication at the beginning of this year...And it was kind of like an accident, an incident that I forgot giving her medication one time and she was at Grandma's house and I thought she took it. And all this time, when she came back home a couple days, my mom said, "She didn't have them, she didn't bring no medication." And I'm like, "Oh my God, she's doing good." But when I was giving her the medication, she was like worse. So hold on...I said to myself, "I know this is something I need to talk to them about before I make any decisions. But if I see my child doing better, I'm just going to hold myself until I see the doctor." So what I did, I just lowered her doses and so I stopped giving it to her until the time of her appointment...But since the time I stopped until I saw [MD], probably two or three months passed, she was doing okay. So that's why I spoke with [MD]. I said, "When it's going to be her next MRI?" And [MD] said, "Well, she's doing wonderful, I don't think she needs that MRI until a whole year." And I said to him, "I'm going to be honest with you, and this is what happened." So that's when they decided to do the MRI and all the tests and everything came out stable... But they still wanted me to go back to the medication. I said, "Why should I? If you tell me that something's wrong, I will think about it and figure it out to take-- put her back on the medication. But you tell me everything's stable. I don't feel comfortable giving*

*her something that she doesn't need" ... Yeah, it sounds weird but since she's been not taking it, she's been less in the hospital.*

She related her decision not to maintain treatment to the variability in the effect of MS from day to day and medical science's limited understanding of its effects.

*It kind of damaged her eye, her right eye. She can't really see well. But for some reason, some days she wakes up and she sees better than other days. And that's the mystery of it. I saw her doctor last week, and [MD] felt a little bit concern about her eye. [MD] did some basic studies and her eyes wasn't responding. But the same time, when [MD] pulled the lid, the light in front of her eye, was reacting. So, [MD] felt, "Oh, my God, how her eye's reacting when her eye's not acting the way it should be?"*

The mother quoted above who had concerns about whether a particular DMT was safe at her daughter's age discontinued the medication in favor a naturopathic method, influenced by how well her daughter was doing. But they returned to the DMT when symptoms "crept back in." Her words reflect the unpredictability of the illness, the lack of certainty that treatment will be effective, and the feeling of helplessness that can undermine the treatment process:

*I basically said to the doctor, "Well, you're right, I'm wrong and it's happened again. And I guess it wasn't a smart choice to take her off," but there is no good choice in any of this anyway.*

## **Summary**

All of the youths in these families were receiving disease-modifying medication except for one who was about to begin at the time of the interview. Most youths were either experiencing no symptoms or their symptoms had limited impact at the time of the interview. Children, their families and their neurologists usually worked together to make treatment decisions. Finding the right medication was often a process of trial and error. Several youths tried several different medications before they found one that appeared to be effective and had side effects that youths could bear. Most youths were treated with IV

methylprednisolone when they were symptomatic, which was effective for most but not all youths, but often had difficult side effects. The biggest challenge with disease-modifying treatment was the difficulty of injections, because of pain, bruising, flu-like side effects, anxiety and dislike, difficulties maintaining privacy about the illness, and concern about the use of injectable medication in pediatric cases. These difficulties influenced a switch to oral medication in some cases.

## Chapter 6

### Pediatric Multiple Sclerosis and School

*It's just always a struggle. Some teachers are really understanding. They know she has got an illness. And others are just, they don't understand.*

#### Effects of MS at School

Pediatric MS can pose challenges at school in many ways. A number of youths discussed in the sample had cognitive changes due to MS<sup>23</sup> that impaired their learning; in several cases these were identified through neuropsychological testing conducted by the centers. Many students had greater trouble with day-to-day schoolwork when they were experiencing symptoms of MS. Fatigue from MS was also a problem, making it harder for students to persist with schoolwork and manage their homework. Getting work done on time could be difficult. Some student's grades and standardized test scores had dropped. Big class projects, the kind that ambitious students need to help them get into college, could be particularly challenging both because of the effects of the illness on learning activities and the amount of time the illness forced students to miss school.

The effects of MS on schoolwork could be subtle and complicated. They may have appeared before the diagnosis was made, which made it more difficult at that point to identify the learning problem accurately and respond. Parents needed to carefully track the diseases' effect on schoolwork and advocate in a timely way. One parent gave this example of how the speed of information processing was impacted by MS:

*The teacher said, "Well, she just has a speed issue. She needs to pick up her speed. She doesn't have a cognitive issue, it's a speed thing." And I said, "Okay." So, I said, "You know, she's been tired lately, I understand that." She goes, "No, she needs to pick up her speed." I'm like, "Okay, I get you." But then she'd come home and do her homework. No, she didn't have the speed, which was the MS probably, but cognitively she was*

*perfectly fine. And then I showed the teacher this year, I said, "I don't think my kid was in the right class last year because this is the national test. She's proficient with distinction in math and reading. And then you have her in the lower math class" ...And then, of course, the MS thing happened and it's like, "Okay, this is what it is. The whole time she was having issues, it's because her eyes were going or something was happening." So the teachers, you know, I just asked the teacher, I said, "Can you please grade her on what she completes so she doesn't get depressed?"*

Physical symptoms could affect youths' school experience by making it more difficult to function in the school environment. One mother was very concerned about the air conditioning at school because the effect of MS on the student's body temperature.

Managing bathroom activities could be a challenge, as two mothers explained:

*If she has an accident going to the bathroom, I'm worried about that, and I've talked to the teacher about it. I said, "Make sure that no one restricts her to go to the bathroom, please." Because that would be the most horrible thing to happen in school to her, and I don't even know what I'm going to do if it does happen because it's going to shatter her.*

*I guess she raised her hand but called help at the same time that she had to go to the bathroom. I'm not sure how that went. They didn't allow her to go to the bathroom. So, she peed on herself. I'm sorry, but I went in there like guns blazing. She was embarrassed, she embarrassed herself. She didn't even want to go back to school. So what did I have to do? Have a meeting with the teacher myself. First I told them, don't you ever deny my child to go to the bathroom. Sorry, I said that. And then I explained to him. "Oh, I wasn't aware." I say, "Yeah, of course you weren't aware. Of course you weren't because they weren't doing their job. They didn't do their job to make you aware of this fact that you cannot deny my child to go to the bathroom. She can't hold it like everybody else."*

Sometimes the most frustrating effects of MS were on extra-curricular activities: one student was particularly disappointed when MS prevented her from playing sports, which not only eliminated her favorite form of recreation but took her away from her teammates.

Treatment could interfere with school. Some students missed school or class time because of the flu-like side effects of a medication, as one mother explained:

*Almost every day, she was seeing the nurse. But it was because of the medication. They didn't understand, there was a point that they felt that she's probably making this up, she'd get out of her class.*

Another girl receiving treatment became worried because of concerns that her medication weakened her immune system; as her mother said, “*She got paranoid at school because there was a girl sick, coughing in front of her so she had to leave the school.*” Because side effects from injections could interfere with school functioning, family scheduled injections for the weekend, which had the disadvantage of cutting into the young person’s social life. Students getting injections were concerned about weight gain as a possible side effect, which might be noticed at school. One boy was teased about being fat and he shot back, “*I’m not fat, I’m sick.*”

### **Succeeding at School Despite MS**

Despite the challenges of pediatric MS, many youngsters functioned at their usual level of school performance, either because their illness was well-managed with treatment, their symptoms did not affect their school functioning, or they were able to overcome the impact of MS on their learning. A number of students who had excelled at school before MS continued to do so, while others’ difficulties with school were similar to what they experienced before MS. Many had impressive accomplishments. One was a member of the National Honor Society who had completed a student exchange program in Spain. Another stayed after school to do advanced placement art. A number were active in sports, including several basketball players (one the team captain), a varsity cheerleader, and a lacrosse goalie. Other activities included drama, a show choir, a girls’

leadership program, and an after-school job. One mother described her daughter's accomplishment:

*[My daughter] is 'helpy helperton'. She has always loved to help. And there is a lot of kids with special needs in her school, and she is a big advocate for that. There is one little boy that can't talk, and she, the bus monitors were tying him down on a seat, and she videotaped it and gave it to the Principal to let her know what she was doing. She was like, "This isn't right." She loves the little boy. What did she call him? She said, "That's my little cousin. I have to help him, because he can't talk... She is going to be a great doctor one day."*

### **Communication with the School**

Parents had to manage most of the communication with the school about their child's MS, although the pediatric MS centers contributed by providing documentation about the illness. Often parents shared a great deal with the school and made a point of providing details to teachers, guidance counselors and other school staff. In other cases, the young people with MS and their parents were selective about with whom they shared information and what they shared. One daughter was reluctant to tell the school anything because she did not want to be treated differently than her peers, but her mother insisted on providing her school at least some information, reasoning that situations might arise that the school needed to respond to the MS. Communication with schools was a substantial ongoing demand on parents. Schools needed to be updated about changes in the illness, to be monitored for compliance with accommodation plans, and to be told about new problems that arose as the illness and school expectations and activities changed over time.

### **Support from the School**

Most of these students needed at least some support from school, but the supportiveness of school staff varied considerably across families. Families relied on a

range of different contact people, including principals, guidance counselors, school nurses, an LD teacher, a special education coordinator, an occupational therapist, and even a principal's secretary. Here are some descriptions of substantial support from the school:

*She'll miss school or she'll come back and she can't walk or she can't write, and just to make sure that nobody makes fun of her or anything like that they are very attentive in that way. They always go out of their way to accommodate whatever she might need when she relapses.*

*We sent all the medical information about [her daughter] to the school and it got distributed to all her teachers so they know about [her]. And they are really helpful because she got like-- I think it's like 15 minutes every week, she got to see her LD [learning disabilities] teacher. Any concerns that she has, any questions, anything that she doesn't understand. They are there for her. And they know that [she] needs special [help]-- an extra book, a special instruction, or she can take notes from her other classmates in case she's absent. So they know all about that and they're very helpful.*

At the other end of the spectrum, a few parents described school personnel's lack of understanding and opposition to accommodations, forcing parents to advocate strenuously on their children's behalf. One mother said, "But when she needs extra help or extra time, she asks for it, they don't give it to her." One mother described substantial skepticism at school:

*It's almost like they're making her feel bad that she has it. They question whether she asks to leave the room sometimes a few minutes early before class, and the teacher's like, "Okay, kids. Is [youth name] just being lazy or does she want to leave for other reasons?" ... my mother has been a special ed teacher for over 30 years ...and she said when she saw my daughter's IEP [Individual Educational Plan], she didn't see her medical condition or anything on there... it's been 14 months and her IEP is definitely out of date.*

Other families were in-between: families might have several champions at school, but also had to face teachers who did not appreciate the effects of MS and resisted making adjustments. Here is one mother's description:

*It's just always a struggle. Some teachers are really understanding. They know she has got an illness. And others are just, they don't understand.*

One challenge is that the needs of students contending with MS were missed because the effects of MS, such as fatigue, are often invisible to most people. Sometimes teachers or other school staff did not find students and families' reports of difficulties credible because the students looked "normal." As one mother described:

*I think [Name]'s illness threw them for a total loop because physically you look at him and you think nothing's wrong with him. So I think when the teachers get him in a classroom, they're like, what is this mother talking about? The MS guide for teachers, Teacher's Guide to a Student with MS is the best— I make photocopies of that every year.*

### **Accommodations**

Section 504 of the U.S. Rehabilitation Act of 1973 entitles students with physical and mental impairments to accommodations in their school experience. Many of the students had 504 plans and/or the similar Individual Education Plans (IEPs) to compensate for the effects of MS. The interviews did not go into detail about what specific accommodations students had, although it was clear that one important one was extra time to complete schoolwork. Nor did we assess thoroughly the impact of accommodations, although our impression is that it was helpful to have them. Of course, that depended on having an adequate plan and having school staff follow the plan. One mother talked about having to confront a stubborn teacher who would not follow the 504 plan. One challenge was that it could be difficult to specify a particular standard accommodation for a student, because of the variable nature of MS. One mother explained:

*All the teachers are meeting next week and I have sent them all an email and said, "We can't say what special accommodations she will need every*

*day, because it changes every day, and you just have to trust that she is not trying to be disruptive or disrespectful, but if she is having an allergic reaction and her throat is closing she is leaving your class.” And they were like, “All right, all right.”*

Some families did not have 504 plans. One parent reported being assured that a letter was sent to the school and the 504 would be in place, only to find that the school was not aware or prepared at all. A few parents were not aware of 504 as an option or had been too busy to pursue it. Some students had only minor accommodations (e.g., extra time on tests) and it was not clear whether they had a formal plan for providing them or received them informally.

Some students and families did not want accommodations, feeling that this would label students as different. In some cases, there was simply no need, as the MS did not affect school functioning. In other cases, youths and their parents were aware of the impact of MS on school functioning, but saw a disadvantage to accommodations. They wanted to be treated as ‘normal’ and felt that they could meet standard expectations. Another motivation was to avoid lowering academic expectations and thereby potentially lowering performance. Here are examples:

*When it comes to the school situation, he has not asked for any of the special treatment that is allowed, we know is still available and everything that goes on with it. And still to this point, he's been very good with it and not really wanting to push.*

*It's like even when I go to IEP meetings, they're like, "Well, why don't we let [Name] do"— and I say, "No," I go, "you lower that bar once, we're going to keep dropping it." And I said, "The bar's not being lowered. We're not going to lower it. It needs to stay up here. I'll lower it if he's on death row. But for now, he's capable of doing it. We just need to figure out how...Honestly, my attitude is dwelling on all the negative and all these special accommodations, it's going to make him not mainstream. It's going to encourage him not to be like everybody else. And I don't want him to feel like that.*

One related concern was preparing for college, which would treat the student differently than high school. One parent said this:

*And hopefully next year, or this upcoming school year, she'll do much better. She has no choice, it's going to be college. Colleges are going to be really scrutinizing this year. So she knows that she has a tough road ahead of her and she just has to work really hard to get to that point, you know?*

### **Missing School**

Almost all the young people with MS had missed school because of hospitalization, or the symptoms of the MS, or the side effects of DMTs. This put them behind in their school work and made them work hard to catch up. Sometimes this was overwhelming. One mother talked about how teachers would expect her daughter to make up work at home when she missed days in school, and did not realize her symptoms were making it impossible for her to do work at home.

Students would occasionally cite their illness to take time off from school or avoid other school expectations, and it could sometimes be difficult to determine if their request was legitimate. Here are two examples

*He left school a lot because of headaches and we don't really know-- we never knew whether to believe him or not. And I think sometimes he uses this to get out of things.*

*He's like, "I'm just tired." I said, "Okay, I'll call you out [from school]." ...And he later confessed and said, "I just didn't feel like getting up." I said, "That's okay. That's okay. Sometimes you're going to feel like that, it's okay. It's okay to get sick, it's okay to be tired, but you got to tell me what." This morning he didn't get up until 11. He's like, "I'm tired." I'm like, "Okay, all right. Just eat something."*

One student was absent because he was overwhelmed and not because medical issues. It nevertheless signaled a need for parents and school staff to respond compassionately.

*I, we've had our issue where he knows I'm so sensitive to him. It's, "Oh Mom, I feel off. I need a day off." Next thing I know, he missed 30 days of school last quarter, 30 days. And he admitted most of those-- some of those he played me because he just got so far behind and I had to meet with the school two weeks ago, meet with all his teachers and the counselor and say, "Listen, [he] has illnesses and he's 15 and he's behind and he's overwhelmed. And how are we going to fix that?"*

Self-consciousness about symptoms could be a reason for missing school, as one mother explained: *"Sometimes she just doesn't want to go to school because she doesn't want people looking at her."*

Some parents felt they could trust their children not to take advantage of their illness to miss school unnecessarily. Others felt that they could do an assessment and determine whether their child truly needed to stay home. Here are three parents' descriptions:

*Oh, yeah. I kind of know when she's really not feeling well and it depends what I see, that's the decision I make. If I see that she stops in two hours, her shaking, she's ready to go to school...I just watch and see.*

*I'm like, "Okay, tell me what it really feels like," because he won't tell me anything. So I get that the fatigue...is...they're like you can't move your arms, you can't lift your legs; it's that tiring. I'm like, really? And they're like, yes. So when I looked at him, I knew he wasn't fooling me. And I said, "All right, go back to sleep." He doesn't use it as much as he used to, because he's now realizing he can't miss school that much anymore, because then he gets really far behind. So he takes ownership.*

*I do a few things that I see the doctors do, not that I know what I'm really doing, but if something is really wrong, I'm going to see something because every time they've done it, and I've seen something wrong, is when she's been sick. So I kind of try to do different things to see and I can usually tell between don't feel like going and don't want to go. That's kind*

*of a fine line, especially when it's just myself making the decision, but I've kind of got a pretty good idea of when I don't feel good and I don't want to be around. So I still need a little work on it, but I think I'm getting pretty good at it.*

Some students had incidents in which they wanted to go to school despite symptoms and parents had to insist they stay at home or get medical care because it was necessary. Here are two cases:

*Actually he fights to go to school. I am the one who says, "Okay, if you're not feeling okay rest. Health is first. When you feel okay then you come back to school." "No, I have to go. I have a test. I don't mind."*

*Time out of school really annoys him because he's like, "I'm going to fall behind. I'm going to miss this. I'm going to--" and I'm like, "You have an IEP, you have a 504. Your health comes first. I don't really care how you feel right now. We're going to the doctor's and that's that."*

It could be challenging to decide how many days a student should miss.

Sometimes there was a tension between making sure to give the student enough time at home to recover and the student's wish to return to school, as two mothers described:

*If she misses a day, she's probably going to really be feeling bad. And maybe the next day might not be feeling 100%, but wants to be in the class. So it's almost like I wish they would give her a little more time.*

*She has wanted to go [to school] and I didn't think she should, and I'm glad she wants to. She said, "...I don't want to miss too many days at the beginning of the year." But I had to go get her early. She missed today and I had to dismiss her early twice this week, because she wasn't feeling well, and I'm already just kind of like [sighs]. It's a lot, you know? I just feel like I can't leave the house sometimes. But that's how it's going to be for a little while until we get it all sorted out.*

### **Relationship with Peers**

When asking about school, we also inquired about the effects of MS on peer relationships. Parents' responses to this question varied. We heard in the great majority of the interviews that either the youth's friendships were not affected or they were strengthened since the diagnosis of MS. That being said, some of the young people with

MS who were described to us were self-conscious about their illness or withdrew from others in response to their difficulties. Some youths were more open than others about the illness. Typically, youths told friends who really mattered to them about the illness, but did not tell other peers. Given the impact of MS on school and the school days missed, word of the MS often traveled through school anyway, which is why some youths were wary of telling anyone at school. Most youths were able to continue socializing with their peers as before, but had to miss certain opportunities just as they sometimes had to miss school. In a few cases, peers actively supported the youth in responding to the illness, like the one friend who came to the youth's hospital to play video games with him and the fellow cheerleaders who came to cheer on a youth with MS participating in an MS Walk.

### **Summary**

A number of youths discussed in the sample had cognitive changes due to MS that impaired their learning, sometimes in subtle and complicated ways. Physical symptoms could affect youths' school experience by making it more difficult to function in the school physical environment. Sometimes the most frustrating effects of MS were on extra-curricular activities. Despite the challenges of pediatric MS, many youngsters functioned at their usual level of school performance. Many had impressive accomplishments. Communication was a substantial demand: schools needed to be updated about changes in the illness, to be monitored for compliance with accommodation plans, and to be told about new problems that arose. Youths and parents were selective about what they shared with school staff and classmates. Most youths with MS needed at least some support from school. Some youths received substantial support from their school, but in others school personnel's lack of understanding and opposition

to accommodations forced parents to advocate strenuously on their children's behalf. Sometimes teachers did not find families' description of problems credible because the invisible symptoms of MS left students looking "normal." Many students had formal and/or informal accommodations at school, but sometimes schools had inadequate accommodations or certain teachers would not follow them. Some youths and families did not want accommodations, feeling that this would label students as different. Almost all the young people with MS had missed school because of the illness, and degree to which this put them behind was sometimes overwhelming, particularly when teachers did not realize they were not well enough to do the work at home. In some cases, parents felt youths took advantage of the diagnosis to avoid school demands, but just as often youths were pushing to return to school and parents had to hold them back to protect their health. For most youths, their relationships with their classmates were not affected by the illness or were strengthened, though youths sometimes had to miss social activities.

## Chapter 7

### Adaptation, Resilience, and Concerns about the Future

*“...I was watching her play basketball the other day and it just hit me...she has MS and she's out there playing ... She's doing what she wants to do.”*

As we mentioned briefly in Chapter 4, most young people with MS and their parents and siblings had adapted to the illness over the course of months or years: the median time they had had MS was nearly two years. They had overcome the worst difficulties of the illness. Chapter 5 discusses how most youths were receiving disease-modifying treatments and most were asymptomatic or had limited impact from symptoms. Many, though not all youths were doing well, enjoying life, achieving success and making progress in growing up. Families were aware, however, that MS still affected their lives and were concerned about its impact on their children's future.

In this chapter, we provide more detail on how youths and their families were resilient and adapted to the illness. We also discuss the role of the National Multiple Sclerosis Society in helping families cope, and parents' contact with other families living with pediatric MS. Finally, we discuss parents' concerns about their children's future.

Several youths excelled in school, sports or a part-time job despite the MS. These activities provided structure in youth's lives and gave their families the feeling of having prevailed over the MS. One mother and father described how proud they felt watching their daughter:

*But I was watching her play basketball the other day and it just hit me, like, you know, she has MS and she's out there playing ...I almost was going to cry in the middle of the stands, you know? She's doing what she wants to do. She couldn't start, she couldn't play basketball when she was supposed to. She couldn't start for almost a month because they were having practice. She couldn't even try out for JV... if the [other parents]*

*knew what [Name] had to overcome to get onto the court... she fought for it. And when one doctor told her, "Wait to see [MD] before you play," she was ... was so frustrated. She just started crying because she wanted to play. [But her neurologist approved it and said] "You've got to live a normal life."*

Often there was a mix of resilience and difficulty; one mother described the mix of social strengths and struggles affecting her son:

*During basketball season, he seemed to have a lot of friends. I'd pick him up from practice. "Hey, [Name]." [Name] made captain, everybody loved him. Coach come up to me, tell me what a great kid he is and he wished the kids worked as hard as him and how he's a leader. But I don't see him with friends.*

For many parents, the most powerful resource for coping with MS was their extended family. Some parents reported that they received the diagnosis of MS with a number of family members gathered in the hospital room to support their child and them. Most parents had a number of family members who had supported them with their love, their time and their material resources. A few parents had extended family members who were not engaged or supportive, and they looked instead to friends for support.

Parents talked about adjusting their way of thinking to cope with the illness. Sometimes family members reminded themselves "it could be worse." Several parents adopted a philosophy of living "one day at time" and dealing mentally with any problems with the illness only as they emerged. One mother put it this way:

*I'm just giving it up because how can we live in fear every single day that it's going to happen again? So instead, I'm basically saying, "Okay, when it happens, we'll deal with it. If it doesn't happen, let's get it out of our minds because it'll drive you crazy."*

Advances in the treatment of MS have given families hope and helped them cope. One youngster was depressed about his illness and predicted that he would be dead or in

a wheelchair in his 30's. His mother pointed out the development of disease-modifying treatment in recent years and forecasted continued progress over the next decades, and told him confidently that he would not end up in a wheelchair in his 30's.

Religious faith was an important resource in several families. One youth whose faith helped her face her diagnosis calmly was mentioned above. Some parents felt comforted and strengthened through their belief that God was with them throughout the difficult process of dealing with pediatric MS. They trusted in God's response to alleviate suffering and bring meaning to the difficulties of life. One family looked forward to a day in which the power of God would transcend disease. Parents would talk about their own faith in God and sometimes about the youth's faith and the positive effects for each family member during the illness. Several parents credited their children's faith with giving the emotional resilience they needed to handle the illness calmly and confidently:

*If she still has the faith in God and the power that she can do stuff, she can do it.*

*Her faith is so big that she was normal [when she received the diagnosis] ...Yeah. She says she has God and she has a family that was there and she was okay. She always says that ...She's very positive. To her, this is nothing.*

Some parents thanked God that the effect of the disease was more limited than the negative descriptions in the medical literature:

*But at the same time even if it is a big issue it's nothing, because nothing happened, thank God. It's a lot on our mind, but nothing is happening. So it's like God is telling me even though what they say, this is what I say.*

One family thought that their son's ability to face the disease with God's help would be testimony to God's gifts:

*People in the future are going to look at my son and they are going to see, they are going to see, “I saw this kid when he was a little, facing so many challenges, and look at where he is right now, because God is holding him by his hand.*

### **Experiences with the National Multiple Sclerosis Society and with Other Families**

The National Multiple Sclerosis Society has taken steps to address the needs of children and adolescents with MS and their families. The NMSS provided funding for the establishment of seven Pediatric MS Centers across the United States in 2006,<sup>24</sup> and there are now twelve centers across the US. Local chapters of the NMSS provide services to both children and adults living with MS and their families. The Greater New England Chapter of the NMSS has also collaborated with the pediatric MS centers to hold weekend family programs and other educational programs. The chapter also helps to arrange connections between parents who have a child with MS, reducing their sense of isolation, and providing a chance to ‘compare notes.’

We asked families about their experiences with the NMSS. In the course of these conversations, parents also talked about contacts with other families affected by MS, made either through the NMSS or independently. Most families had benefited from their interactions with the NMSS, and it was a regular source of support for some. Since POMS is uncommon, none of the families had ever met another family with a child with MS previously, and several families found these connections important. One mother was helped by the NMSS after overcoming some initial reluctance:

*When we were first diagnosed, they [the MS Society] were calling and I'm like, I'm not talking to these people. Partly denial, partly because I'm a very private person. I'm like, I'm not telling anybody anything...And then when I got all that stuff in the mail, the parents' guide to MS, a teacher's guide to a student with MS, and I'm flipping through them, I'm like, wow. So then I got to know [MS Society staff person]...and I was like so- the stupidest little thing you have, they'll, "What do you want?" And then [she's] always sending me, "What about this meeting" And I'm like, "But I don't have MS." She's like, "That's okay. You should still go."*

One mother talked about how her daughter loved the MS camp and both she and her daughter had met new friends through it. It was powerful to make contact with and receive and give support with so many other people who were also living with MS.

Another mother said this about her daughter's experience there:

*She's not alone. She can share with anybody her feelings and all the treatments that she learned...*

It could be helpful to discover that others were worse off. One mother explained:

*Honestly, believe it or not, oh my God, the first-- the first meeting we went to, all the people. I thought like, "There's a lot of people out there, a lot of people out there." And I do like to go into those meetings-- no, when she's gone, there goes my meetings... I love those. I love those, I really do. You get to share the stories. You get to see you're not as bad. It makes you feel, okay, there's someone worse than you. I mean, and kids so young. My God, they're so young, you know?*

It could also be helpful to hear lessons learned by others:

*...The first meeting we went to, there was a girl there. She was older but young, like in her 20s, already using a cane. She said, "You know, I went to college and-- because I felt better, I stopped taking the injections and then I had to go on steroids. And this is why I use the cane, because when I was feeling better I stopped my medication. So whatever you do, don't ever, ever stop your medication because from so much steroids, this is what happens to your bones." And I'm telling you, [my daughter]'s oh so [careful] with her medication because of her.*

MS events gave youths an opportunity to feel they were successful and contributing despite their illness. One family did the MS walk, so their child "can see at

*least a positive from everything she's going through.*” The MS Society could also help make connections to other families apart from the events: the Society was helping to connect one girl in a family we interviewed with another girl with MS of a similar age who could serve as a mentor.

Financial support from the MS Society could be an important resource:

*And if we ever need anything, we call them. She needed some cooling equipment and some other things in the beginning, air conditioner, and they willingly bought all of that for her, which was really-- my husband and I were really thankful that they did that for her.*

*...on the [DMT], there was a \$200 co pay and we can't afford that. So I'm like, "What am I going to do?...I don't have \$200 right now." So, I called the MS Society -- there's so many resources if you look for them... They cover ...the \$200 co pay...every month...for a year.*

Informational support was important as well. One mother was grateful that the MS Society was available by telephone to answer her questions when confusing and disturbing symptoms arose.

Youths could be resistant to contact with the NMSS, however, out of a wish to be “normal” and not have to think any more about the illness than necessary:

*I tried to find somebody that she might be able to identify with, and it was really hard to find somebody, and I finally did find somebody, but she didn't live close to us. She probably lived about 45 minutes away from us. And we met with her and her mom and her sister, and with [name], and they kind of met. And it was good for [name] to have somebody that she would be able to talk to, somebody who would kind of identify with the things she was going through. But they really just didn't hit it off. [name] just doesn't talk about it with anybody... She just doesn't want to be different.*

*I think one of the things that we'll end up doing-- I think, if I can convince her, to get in touch with this mentor [through the MS Society}; somebody that she can talk to that has gone through it. She's very personal when it comes to that kind of stuff and not wanting to just talk about it a lot.*

*No, she doesn't want to [get involved with the MS Society]. She says we don't need it, we can get out through-- as a family... she wants to keep it personal. She doesn't want everybody to know she has MS. She doesn't want anyone to treat her differently, not to think anything of her differently.*

*And my outlook is hey, you know what? If he really wants to [attend MS Camp], he'll say yes, or he wants to meet people or do whatever, he'll say yes and do whatever, you know what I mean? And that's where I really feel that he still is in denial. I mean, he understands, but he is in denial and he doesn't want to-- I think he feels if he starts going to some of these camps or whatever, that he might start feel like he's embracing it and that this is my life for the remainder of it. And I think he's really trying to say, "You know what? This is how I'm going to live life. I might have it, but you know what? I'm not showing my colors, this is how it's going. I'm going to try to live life as normal as I can, and so on and so forth."*

*You know, I brought it up to him [MS camp] and he was just like, "Not interested." I'm like, "Okay, well, we'll revisit that again." We're still trying to work out [meeting another boy with MS], so that he knows there's somebody else like him. With him, it's all baby steps and you've got to sell it to him or it's not happening.*

*We get all these invites to go to these MS lectures and all these things and he's always like, "No, Mom, we ain't going. Those are dumb, those are dumb." And I just said to him last night that, "You know what...? You and I need to go to a couple of them. You just really need to sit and hear it and understand this disease better. ... you and I both don't get exactly what's going on. We don't even know anybody that has your disease." You know, it would be nice to mingle and help us understand by meeting people and doing things. So I kind of got him on board, I think, by the time he'll do it for me just to do it.*

Some parents we interviewed had had little or no contact with the MS Society.

One mother did not know that there was a local branch based in her state. Another mother found that the local MS support group, consisting of adults with MS rather than parents of children with MS, was not helpful to her.

Sometimes families had only had a brief contact with the MS Society through participation in an event, including MS Walks, an MS bicycle race, a trip to a

professional baseball game organized by the MS Society, and an MS mud obstacle course. Sometimes these would be opportunities for friends to support the child and family; one mother reported:

*We're doing a MS walk...in a couple of weeks ...and her whole cheer team is coming to cheer her on and walk with us.*

Parents have met other parents of youths with MS through these events and have occasionally maintained contact through telephone, social media and texting. A few parents and their children had had a brief exposure to the MS Society but were considering more active participation (e.g., in summer camps or a lecture series) in the near future.

For most families, involvement with the MS Society occurred months or even years after the diagnosis, because so much of their time and energy was spent dealing directly with the illness when it was new to them. Several families we talked to seemed simply not to be relatively new to the illness and not ready to engage with the NMSS.

Sometimes families felt they needed just a modest amount of support from the MS Society, as this mother explained:

*She [her daughter] gets newsletters from...the National MS Society, and so do I. So sometimes we each find an article on there that was kind of interesting, we'll share that kind of stuff... She just did the walk for the National MS Society this year with a team of kids and raised a bunch of money and had a great time. So, I mean really the only discussions that we ever have about it are ways to be involved or positive... I would also say the information I get from the National MS Society [has been helpful], they've been really great and some of the options they provide for people to talk to each other...I emailed a parent that also has a pediatric MS child and we emailed for a while, but I think she and I both realized that we were in good places. Occasionally, we'll touch base, see how things are going but for the most part, you know, I don't feel the need to constantly reach out to other people to talk about it. I'm not struggling with the diagnosis or any of that kind of stuff...our schedule's so busy,*

*even if they had more stuff, I don't even know that we could participate in it.*

One concern was the effect of seeing other people with MS who were more disabled. One mother said,

*I didn't want him to see people in wheelchairs, so I kind of never gave him the card to go to the [professional baseball] game [outing organized by the MS Society].*

But her son did go to an MS Camp where “he got to meet a lot of kids his age that have been diagnosed with MS” and did plan to participate in an MS Walk.

However, not every parent wants this type of contact:

*You know, I've called her [another mother of a child with MS] with questions and the first conversation with her was very difficult. First thing out of her mouth was, “How many lesions you got?” And for me that was like, stabbing me. And I was like, “What?” I didn't want to know how many her son had.*

Some families learned about MS through members of their community and through social media, independently from the important role the NMSS plays in helping families become familiar with MS. Another parent had a personal acquaintance:

*I know a young girl-- she's older than my daughter-- that is our friend; she has MS, too. ... when my daughter was in the hospital, she came to visit her and when I see her, I hug her and I start to cry with her because I know that she has that disease, too.*

One family revealed that soon after their child’s diagnosis, they learned of many families affected about MS.

*All of a sudden we just started [hearing], “Oh well, Mom, my friend’s mother has MS.” You know, like that. I'm like, “Really?” Like, you know, now it’s like, oh now we're getting to know people who have MS. Or, somebody’s friend or-- I don't know, it was just weird how it went. It's like when you got a white Subaru, everybody now has a white Subaru, you know?*

## Concerns about the Future

We asked parents what their major concerns for the future were about their child's MS. Parents' overriding concern was the possibility that the illness would in the future rob their children of independence, self-sufficiency and quality of life. They thought about how they would eventually not be around to take care of their children.

*I do worry about that a lot. I do. [crying] I think, is he going to be able to have a job? Is he going to be able to work? And take care of himself?*

*She doesn't have any brothers or sisters. I think about who is going to take care of her when I'm gone...Is she going to be independent? Is she going to be all right on her own?... I would hate for her to not be able to use her motor skills anymore, because she won't have a full life, she won't be able to experience a lot of the things that I was able to experience, and I want her to experience more than I've been able to do, and I've done a lot... if she loses her motor skills or she is unable to do these things she can't be whatever she wants to be. That's scary. That's scary.*

Fears of future disability were expressed in most of the interviews. The image of their child in a wheelchair was frequently mentioned.

*Well, one of the things that concerned me that they said she probably can end up in a wheelchair in the future. Or not be able to have kids. It all depends.*

*It's the unknown. Is my child going to end up in a wheelchair? Is he going to have difficulty with his limbs? Is he going to have vision?... I wish there was a roadmap that would tell me what to expect. And Type A in my head says, "I need to know this." But I'm not going to because it's not how this disease is.*

*We worry about how much is his MS going to progress...Hopefully not to the point where he's in a wheelchair or anything like that. Hopefully he never gets to that point.*

*I worry about me not being around for him... If I have a heart attack or-- what is he going to do?...I'll always take care of him. I have no problem. I'll move into a building with a damn elevator if I need to push him around... but I'm the only one that he's got, so I worry about what if*

*something ever happened to me...Because what if he ends up in a wheelchair and he can't walk and he can't feed himself?*

*Could she live to 50, 60 without being in a wheelchair or bedridden?  
Great. I'll be dead by then...I mean? I don't want to have to see my kid not [be able] to take care of herself.*

Some parents worried that disease-modifying medications would not be effective or available. As one mother said, *"My major concerns are that the drugs will not work. He will progressively get worse and things will spiral."* One family's concern was about the ability to pay for medication in the future -- the two years of free medication from a pharmaceutical company was running out, and their insurance would not pay the expense.

Parents also worried that the disease would affect their children's ability to enjoy normal young adult and life experiences such as dating, college, marriage, becoming parents, and pursuing careers.

*...Will any other girl like not date him because he has MS?*

*I want her to live a normal life. I want her to experience the boyfriends and the driving and the-- everything I did minus the bad stuff...to have children and not have to ...worry... about the...hereditary part of them having the more likelihood of having it as well... I don't want MS to take it away from her.*

*I don't know if she is going to be able to go away to college. Like the way I see her now I just don't see her being-- But I mean she has only had the diagnosis for three months. But you meet so many people, they're like, "We're fine. We're fine." And then I look at [my daughter] and she is really not. She is really not. So, I don't know. We'll see.*

*Is she going to get married? And if she gets married, is she going to have kids? I know a lot of people who say after they get pregnant, have the baby, they go downhill. So that stays in the back of your mind. Will she ever have a real normal life?*

*What do I prepare him for? How do you prepare him? I haven't dropped certain bombs with him about you'll never be in the military. You'll never be a cop. Fire department's out. Those are things that you can't have that disease and function in. They won't take you.*

One concern about the near future was their adolescent youths' ability to manage the illness without them at college. One mother explained,

*Now she wants to go to college and it's going to be hard, every day a shot and she needs somebody to assist her with the shot, you know?*

*It's going to be hard to send her off to college. I've actually been very vocal about her being close to her sister in school and that they go to the same college because I can't be there...I don't want her to go far, but she wants to go away. And I told her that I don't think it's a good idea because of her illness... if she ever had something happen medically that was an emergency, I can't get to her right away...it's important for me to have a peace of mind that if you're at the same college as your sister, at least you'll have your sister with you if there's any medical emergencies...*

One mother's concern was whether her daughter would make choices to maintain her health as she becomes more independent: "...*That's definitely my biggest concern for her, is that she sees that maintaining good health is going to help her keep MS at bay*"

Some parents expressed hope about the future because of ongoing research on MS. "*The medicine is so much better than it was years ago,*" one parent said. Several mentioned wishing for a cure. One mother was discouraged about this possibility however:

*I don't think they'll ever find a cure. Cancer's running around a lot more than this and they haven't found a cure for that yet.*

## **Summary**

Many though not all youths were doing well, enjoying life, achieving success and making progress in growing up. Families were aware, however, that MS still affected their lives and were concerned about its impact on their children's future. Several youths excelled in school, sports or a part-time job despite the MS. Often there was a mix of resilience and difficulty. For many parents, the most powerful resource for coping with

MS was their extended family. Several parents adopted a philosophy of living “one day at time” and dealing mentally with any problems with the illness only as they emerged.

Advances in treatment for MS has given families hope and helped them cope. Religious faith was an important resource in several of the families we interviewed. Most families had benefited from their interactions with the NMSS, and it was a regular source of support for some. It was powerful to make contact with and receive and give support with so many other families who were also living with MS. MS events gave youths an opportunity to feel they were successful and contributing despite their illness. The NMSS also helped with financial and informational support, and networking with other families. Some youths and/or families limited contact with the NMSS out of a wish to be “normal,” or because of not wanting to think about the illness or see other people who were more disabled. Parents’ overriding concern about the future was the possibility that the illness might someday rob their children of independence, self-sufficiency and quality of life. The image of their child in a wheelchair was frequently mentioned. Some parents worried disease-modifying medications would not be effective, available or affordable. Parents also worried that the disease would affect their children’s ability to enjoy normal young adult and life experiences such as dating, college, marriage, becoming parents, and pursuing careers.

## Chapter 8

### Advice to Other Parents

“We have to have hope.”

We asked both focus group and interview subjects how they would advise parents experiencing the new diagnosis of MS in their child. The discussion evoked useful information which led to the question being asked of each of the parent subjects. The parents were nearly unified in their advice to respond to their child’s illness with a “day to day” approach, focusing on the present. Parents also shared that they understood that their children observed their own responses to the diagnosis and ongoing illness, so they needed to project a positive attitude and calmness. On a practical level, they stated that it quickly became their job to keep track of their child’s symptoms, medications, and reactions. On the social level, some advised parents to participate in the social events in the pediatric MS community; others either had not sought out that community as yet or were uninterested in doing so. Most of the parents expressed the importance of remaining hopeful and shared their strategies to be able to do so when concerns for their child’s future were often on their minds.

#### **Understand that POMS is Most Difficult at the Beginning:**

Parents recalled the initial weeks and months, and how difficult it was to adjust and adapt to their child having a chronic and potentially disabling illness. One parent of a newly diagnosed child shared this comment in response to a question about hope:

*I'm eight weeks in, I don't know what's hopeful. I don't know what's to come. Everything's unknown right now. I don't have anything hopeful.*

The role of support and avoiding “what ifs” was described as helpful in the very beginning:

*That it is difficult, the initial diagnosis and the initial shock of it all is difficult. But with help and support and love from your family, you can get through it. You can get through anything. And you have to really understand what the illness is before you can start judging it. And like anything else, it's what you make of it. Just one day at a time. Don't try to over-think it; don't try to think too far ahead. The 'what ifs,' they're there, but don't concentrate on them too much because-- the 'what ifs' are not going to do it for you...And support is a big thing. Support's very big.*

### **Stay in the Present**

Many parents reported that they handled the unpredictability of their child's illness by using the words, "taking it day by day." In suggesting this strategy to other parents, the subjects expressed their belief that focusing too much on the future was not productive, and could make everyone in the family more fearful and more focused on the illness. Instead, parents described how they focused on the present, trying to be as flexible as possible, and they advised other parents to employ this strategy as well:

*I would tell them that you just have to take it day by day. It's a process and it will be different every time. You can try and prepare yourself for what is next to come. You can try and prepare yourself for their next relapse, but the truth is, it could be different every time, so you're never really prepared... You don't really know what is going to happen next, what could happen next, so you just have to pace yourself.*

*Honestly, I would say just take it day by day and you'll be able to learn when time passes. And don't-- how can I say this? Basically, don't freak out, you know? I know it's a very hard thing, but your child's going to be okay. I mean, just listen to the doctors, to your gut as a mom or father. And then everything will be fine.*

*We were on the fast track before and now we're not on that fast track anymore. And now we're seeing and appreciating little things. And I used to say okay, we've got all this set up and when they go to college, they're going to do this, this... Now, it's you know what? Have a great day at school. You know what? Work as hard as you can at school because you're working towards your future. But, you know, I'm not even going to think about college or any of that stuff with my kids anymore. I'm just trying to get through the next day now. I look at every day now. I'm not even looking at the future.*

*I guess, you know, it's a nerve-wracking experience and you just have to man up. I hate to say it like that, but some days are going to be bad and some days are*

*going to be good. And if you're a controlling person, this disease will take the life out of you. You have to let it go and just do your best because things are out of your control and people-- and I've had to learn that because being a single mom and working two jobs, going to school, and raising my child [that is all I can do]. The first thing I would definitely say is, first, to be positive and not to overwhelm yourself with the future and-- you know what I mean? Because that's what I did. I overwhelmed myself with the future and I just thought negative, like it's a disease. You hear that word disease and it's like the end of the world. So I would definitely tell them to be positive, not to take the word disease so literal like that. Not to think so much about the future.*

### **Manage Your Emotions with Your Child**

The participants advised parents to portray a positive attitude to their children and not show their fear to them. Their experience showed them that the children do better if their parents appear to be handling life with MS.

*The more stressed out you get about it the more that reflects on your child, or your child mirrors that. So, if you make them feel reassured about it, it will take a lot of weight off your shoulders.*

*Doesn't matter how you see your child, be strong for them and give them that strength.*

*I don't want her [the participant's daughter] to think that I'm not thinking positive. I want her to know that she can do this.*

### **Collaborate Closely with Medical Providers**

The participants strongly advised that working closely with health care providers was key to managing MS. They also stressed the importance of involving their child in the communication with their neurologists:

*Oh, okay. I would say just listen to what the doctor tells you. Do the treatment, and everything will be back to normal. You know, you just have to do your treatment and follow whatever the doctors say. Take your medication, whatever, and you will be okay.*

*And talk to the doctors. I have no problem calling the doctors and asking them questions if I don't feel that I have the right information or I don't want to tell her*

*the wrong thing. But yeah, I try to keep the lines of communication open between her and the doctors and whoever is on her treatment team.*

*Make sure your kid is part of the process. Keep them involved; let them make decisions. Let the doctors speak directly to them while you're just kind of sitting there listening. Don't answer for your kid, let your kid answer depending on the age. You know, [Name] was 12 when she was diagnosed, so we let her speak for herself. Even now with [MD], I'm in the room but I want her to do the speaking. I want her to explain what's going on, if anything or where if all is well, all is well.*

### **Participate in the Pediatric MS Community**

It was notable how many study participants recommended that other families involve themselves in community that is developing around pediatric MS:

*And I would say, talk to other people. As much as he doesn't like to go to the events, I go to a lot of the Kids Get MS event stuff. And then I'm also on this—there's a Facebook page, a pediatric MS Facebook page that I love. All these moms and dads out there. Because we're all—I would tell the new parents to find your resources, find someone to talk to, and use that...I love [pediatric MS Facebook page] because one mom was having a hard time with her IEP. And we're all there to say, "This is what you need to do, this is what you need to do," and stuff like that. Then parents, one mom was like, "Okay, we're newly diagnosed. These are the four drugs they're telling us. What are other kids using? What have you found helpful?" I found that to be very helpful.*

The strong sense of community and connection even resulted in an offer to speak to newly diagnosed families:

*But I'll tell you this. If they didn't have a support group, I would definitely exchange phone numbers and start their support system through me and then give them, you know-- if they had a support group I would just tell them what-- at least what your child has is treatable. They work on-- the scientists work on new things all the time. People care about MS because there's walks for them. So, you know what I mean? It's not like a disease that's being left on the back burner. It's full front. There's walks and things you can do to help support the research. So, that's what I probably would say to them. Like, just make sure that they know they're not alone...*

## Maintain Hope

Most participants stated that they would advise newly diagnosed families to be hopeful. We asked them about the sources of their own hopefulness, and their responses reflected a number of sources: their faith, watching their child adapt to life with MS with grace and courage, education about MS, and current research. Here are some examples:

*It's not the end of the world. It's something that nobody wants to live, but it's not the end of the world. There are some parents to whom they tell them, "It's the end. It's over." That's not always the case. It's more like let's work together. Let's cross the bridge together.*

*Life can be good. You just can't let this disease-- and I tell this to [Name] all the time-- you can't let this disease rule your life. You can't let it win. You have to be the one that's in control and in the driver's seat. And fight, you know? And I tell her that all the time. If you succumb to these symptoms and the diagnosis, then it wins. But you need to stay strong and not let this disease get you, you know? I think that's—*

*We have to have hope. And to do what we can do for now, for them, to help them.*

*Look at her [the participant's daughter], she's playing basketball...knowing what she's been through and knowing that she has MS... when you see her out on the court and she's running back and forth and she's doing stuff that she always did, you know? Stay positive because the kid-- the more positive the child is, I think the better off they'll be. Knowing that don't let this knock you down. It may slow you down, don't let it knock you down. You're going to get back up and keep going.*

*...my daughter's a strong, very strong willed child, and she sets her mind to something, she usually does it. She just has to basically get her focus right and I think she can handle this and I think she can maintain her health. I think she just basically has to do what most teenagers have to do, is grow up a little bit and realize that she is a little different, but that only makes her more special. Not different in a bad way, but special. And she can overcome this. It takes time to deal with, process and work through.*

Many parents advised keeping up to date on research and treatment developments for pediatric MS as a source of hopefulness.

*Reading. Researching. That's when I asked you if I'm going to get a copy of what all this is, that's my sanctuary. I feel like if I stay abreast of what's going on, if I kind of keep my finger on the pulse, the hope's not lost.*

*And the good thing to say [that with] new medication coming out, you never know, you know? With any cure, let's see. A lot of people are working hard for that.*

*There is a ton of research going on and there is so much more awareness about it now that I think that there is, it's looking good. I do, I think it's looking good. And early detection, I feel very, that is one thing, I do feel very lucky that we found out early, because I think a lot of people that they get, when they get diagnosed and they say they were diagnosed in their 20s a lot of people look back and go, "Yeah I've had this for a long time." So, early detection is we're lucky to have that, so I would say that.*

## **Summary**

Parents had a considerable amount of practical advice for others facing pediatric MS. They advised other parents to understand that the beginning stage of the illness is the most difficult, but they can cope with the illness if they stay in the present, manage their emotions so they do not stress their child, and collaborate closely with medical providers. Connecting with others in the emerging pediatric MS community can provide added support. Parents stressed the importance of maintaining hope, through such resources as their faith, watching their child adapt to life with MS with grace and courage, education about MS, and current research.

## Chapter 9

### Conclusions and Recommendations

The families affected by pediatric multiple sclerosis whom we interviewed have faced significant challenges, but in the course of meeting these challenges, have demonstrated notable resilience. In this chapter, we offer conclusions drawn from these interviews and discuss their implications for understanding and improving the response to families experiencing pediatric MS.

#### The Impact of Pediatric MS

The negative impact of pediatric MS is a central element of the experience of families affected by the illness, and it was substantial. Symptoms of MS caused motor, sensory and cognitive changes, physical discomfort, and sometimes pain. Long term symptoms interfered with attendance and functioning in school, and many students fell behind. For some youths, MS interfered with their peer relationships, afterschool activities and sports.

The emotional impact of the illness added to the difficulty caused by physical symptoms. In the process of pursuing and receiving a diagnosis, youths and their families experienced periods of shock and emotional turmoil, followed by the ongoing anxiety about the possibility of physical decline or relapses, consistent with Thannhauser's<sup>9, 10</sup> description of the reaction to pediatric MS as a grief experience. Parents experienced a great deal of stress dealing with the emotional impact of a frightening diagnosis, the strains of interacting with medical and educational institutions, and the demands of managing treatment, family relationships, and adaptation to the illness at school. Though many parents testified to the enormous support that they received from hospitals,

physicians and schools, a few reported disappointments from one or the other that left them feeling alone and overwhelmed. These disappointments led to even more demands on parents as they had to advocate strenuously to get the help their family needed.

### **Family Resilience**

Families deserve considerable credit for their resilience in the face of the illness. They endured months of diagnostic uncertainty and often difficult tests to determine the diagnosis. Many parents worked strenuously to learn about the illness themselves, seek second opinions, and hold physicians accountable to double and triple check their diagnostic decisions. Once they received the diagnosis, families countered images of the possibility of frightening physical consequences of MS with a determination to live day by day and meet the disease as it came, just as youths interviewed about coping with MS have reported.<sup>9</sup> Parents were determined to manage their own distress to protect their children's emotional well-being, an approach supported by previous literature on family adaptation to illness.<sup>25, 26</sup> Youths and their families adapted to the demands of the illness and persevered through difficult treatment regimens, usually requiring injectable medication. When asked about possible positive effects of pediatric MS on the family, many talked about how the illness had brought the family closer together and given family members a greater understanding of each other.

### **The Impact of Disease Modifying Treatment**

Despite the difficulties families endured, many of them were doing well and to some degree thriving at the time of the interview. It is beyond the scope of this study to draw conclusions about the efficacy of treatment, but disease-modifying treatment appeared to play an important role in the continued well-being of most young people with

MS in these families. Many of the young people with MS discussed in this study were excelling at school and with peers. Several families no longer talked much about MS because the disease-modifying treatment had become routine, symptoms were having little effect, and youths were not experiencing flare-ups of the illness.

### **The Diagnostic Odyssey**

The long, demanding, and confusing process many families endured to reach a diagnosis is one of the most stressful elements of the experience of pediatric MS. The process of arduously pursuing a difficult-to-find diagnosis has been described as the *diagnostic odyssey*.<sup>23</sup> This is a period in which families had to cope with the symptoms of MS, the enormous adaptations required by the disease and the treatment, the emotional roller coaster of mistaken diagnoses and treatments that failed, and the uncertainties of what was happening to their child and whether he or she would recover. A number of parents, even years after, felt guilty that they were unable to determine what caused their child's treatment, and that their child had to wait a long time for the treatment they needed. Dr. Euan Ashley, co-chair of the National Institute of Health's Undiagnosed Diseases Network, described the problem of the diagnostic odyssey poignantly:<sup>27</sup>

...there's a particular torment that comes from having an undiagnosed illness. Of course you have the symptoms and signs that any illness has, but just not knowing what it is – not having a name for it, not knowing what the course of it is likely to be, not knowing if you share this with any other people – is a severe form of torment.

Thannhauser's<sup>9, 10</sup> interviews with youths with MS confirm that reaching the end of the diagnostic odyssey and being able to label the disease was a significant relief.

The results of our study suggests that alleviating or shortening the diagnostic odyssey would be one of the best methods of enhancing the well-being of families

affected by pediatric MS. We suggest that the NMSS, advocacy organizations, and professional organizations like the American Academy of Neurology, and the Consortium of MS Centers work to educate pediatricians, ophthalmologists, emergency room physicians, and other HCPs. They need to be able to recognize the common early onset symptoms of MS. A variety of methods could be used, including printed materials; articles in journals, newsletters, and other publications; posters and booths at conventions; email blasts; and website postings.

House staff on pediatric neurology wards should also be educated to increase their awareness of the needs and wishes of parents, particularly concerning the disclosure of MS to their children. Several parents did not feel that they were consulted before a medical professional told their child about the diagnosis of MS or provided other important medical information.

### **Support Received and Missed**

Most families we interviewed had received support from family, friends, hospitals, physicians, schools, and, in many cases, the National MS Society. They lavished praise on all those who had helped them. They credited the support with playing a pivotal role in helping them cope with the illness.

But several parents reported disappointments. Some parents reported frustration with diagnostic procedures and treatments that increased discomfort or pain. One family at a tertiary care hospital was intensely involved with a medical center to determine a diagnosis, only to face a six week wait for an outpatient appointment to begin managing the illness. Some parents felt they were short on the information they needed (e.g., in how

to give the injections), while another said it was too much information too soon; “bit by bit” would have been more helpful.

It is not surprising that parents sometimes react with frustration given the stress of the illness itself and the challenges for both treatment providers and families of providing care for youth with MS over time. These results underline the value of a multidisciplinary approach in which professionals with expertise in mental health, psychology and patient advocacy team with parents, youths and treatment providers to help address the emotional impact of the disease and the difficulties of managing the illness over time.

### **Support of Educational Needs**

Almost all parents indicated that some form of accommodation was required for their child in school. These accommodations ranged from providing children access to a bathroom as soon as needed; to allowing lateness and absences related to medical appointments; to specific changes in instruction, governed by 504 plans and Individual Educational Plans. Although some schools and school systems were supportive, parents felt largely unprepared to address their children’s educational needs with school personnel and school systems. Sometimes 504 plans were helpful and sometimes they were inadequate; even good ones were not always followed by every teacher. Parents often had to advocate strenuously to get 504 plans established and implemented.

The Pediatric MS Centers provide support to families in this area. Neuropsychological testing is performed for almost all young people with MS, and Pediatric MS Center staff interact with school personnel. Still, most families felt unprepared for this task. Additional support could be provided by school consultation liaisons provided by hospitals or the NMSS. Professionals knowledgeable about POMS

could participate in 504 and other team meetings. They could offer school staff advice on how to respond to symptoms, and their presence could underline the fact that the youth has an illness that affects their functioning, even if they do not appear sick. School advocacy agencies and organizations could be contracted to provide support, and parents themselves could be trained as educational advocates. Retired teachers could be recruited by the NMSS to provide advocacy locally.

### **The Challenge of Injectable Medications**

Another highly stressful experience for many families was dealing with the difficulties of injectable medication. This appeared to be the first disease modifying treatment for most of the families in the sample. Injectable medication was effective for a number of youths discussed in the study. Yet, while some youths adapted to the medications without undue difficulty, a number experienced injections as painful, frightening, onerous, embarrassing, as interview studies with youth with MS have found.<sup>9 28</sup> Thannhauser<sup>10</sup> has described the conflict that some youths in our study felt between adhering to their injection regimen and their social life as a “medication–peer tug-of-war” that can lead some youths to skip their medication on sleepovers or group outings or simply to enjoy an evening out without having to deal with the medication. Some youths either openly or furtively refused to continue injections, leading to conflict with parents. Others were dependent on their parents to administer the injection, which could limit the youths’ independence. Difficulty with injections was a major factor in some youths’ transition to oral medications. It is not surprising that all of the young persons in Boyd and MacMillan’s interview study of POMS preferred another treatment option if it became available.<sup>28</sup>

Having a problem with injections is not unique to children and youth MS. Many adults have difficulties with self-injection as well, and this is a factor in treatment adherence.<sup>29-31</sup> Likewise, adults with MS also have an interest in seeking oral medication as an alternative to injectable medication.<sup>32</sup>

An effective cognitive-behavioral intervention has been developed to help adults with MS overcome anxiety and other negative reactions to self-injection.<sup>29</sup> This intervention could be adapted for adolescents with MS and their families. Considerable research supports the effectiveness of cognitive-behavioral methods with adolescents<sup>33</sup> which must take into account their level of cognitive development and the important role parents and other family members play in assisting the adolescent.<sup>33</sup> Clinicians working with adults with MS have recommended conducting a family assessment to develop the best plan to maximize adherence to disease-modifying treatment;<sup>31</sup> such a family assessment seems even more important when children and adolescents have MS.

The challenges of injectable medication are likely to continue to be a factor in treatment of pediatric-onset MS for the foreseeable future. The needs of families affected by pediatric MS, however, may play a role in the development of oral medications, through young persons' participation in clinical trials and use of oral medications once they are approved.

### **Pediatric MS and Adolescence**

Most of the youths with MS were adolescents, and this was a factor both in the youths' response to the illness and families' coping. One characteristic of adolescence can be reticence to communicate with parents. Although several youths were communicative about the illness, a number were reluctant to talk about it with their

parents. Reluctance to talk about the MS could also be one way of denying the impact of the illness.<sup>10</sup> Issues of self-sufficiency, choice and independence are characteristic of adolescence, and were also a factor in youths' and families' responses to MS. All families allowed youths at least some voice in decision-making about their illness, and a small number of families turned that decision entirely over to the adolescent, as has been reported in a qualitative study of adolescents with MS.<sup>9</sup> Important decisions included who would administer disease-modifying treatments, and how parents could monitor adherence if their child or adolescent was self-administering the medication.

Professionals working with MS need to have an understanding of how to work with adolescents and partner with families in dealing with the special needs of adolescents for the development of an identity, independence, and peer connection. This requires considerable patience given that these needs will sometimes interfere with adolescents' adherence to treatment regimens. Including mental health professionals with special expertise in adolescent development in a multidisciplinary approach could help families and treatment providers respond to the special needs of young persons with MS at this stage.

### **Meeting the Needs of Parents of Children with MS and their Families**

The National Multiple Sclerosis Society should be acknowledged for the work it has done for children and adolescents with MS and their families. In 2006, the NMSS initiated and funded the creation of what are now 12 Pediatric MS Centers of Excellence,<sup>24</sup> which have focused the efforts of health care providers and researchers in Pediatric MS. Yet there is much more to be done. The health care providers at the Pediatric MS Centers studied were consistently described as enormously helpful to the

study parents. It is likely that this perception applies to the other caring providers who staff pediatric MS centers across the US and Canada. It is important to acknowledge that despite the difficulties living with pediatric MS, the parents we interviewed were meeting the challenge, and they described children who were resilient and tenacious, for the most part continuing with their lives as if they were not living with a chronic neurological illness.

We believe that a move from a patient-centered approach to a family approach is warranted, in which the families living with MS should be the unit of treatment, with an emphasis on the needs of parents. This might require additional staff at centers to address the psychosocial and educational needs of all family members. This would include addressing the need to educate parents and families about MS, treatment choices, and about impact on school, activities, and social life, connect families to each other, and assess how the illness in one child has impacted family function and parental relationships.

Many of the parents interviewed did not feel comfortable attending educational events for adults with MS. They did not find that the educational material spoke to their needs, and they did not wish to meet people with more advanced MS, as they were trying to form an image of the future for their child in which their child could live a full life relatively unencumbered by the impact of MS. The NMSS and other advocacy organizations need to promote interaction of parents who have a child with MS, including in-person contacts, on-line connections, and social media communication. A yearly congress combining parents, young people, researchers and clinicians would be one way of addressing this need. Another would be regular regional meetings of family members.

It is clear from the interviews conducted for this study that the stress on parents of children and adolescents who have MS is great, that the burden of addressing treatment needs is great, and that living with uncertainty about the possible physical and cognitive decline that can occur with MS can be heartbreaking. Parents of young people with MS, and their families, are in need of psychosocial support to help them live with the burden, uncertainty, and heartbreaks of their situation. Psychosocial support can be provided in many ways. The efforts of the National MS Society to help connect families to each other are crucial and should be expanded. Social media such as Facebook groups and teleconferences can be helpful. But for day to day support with the most difficult challenges, mental health care must be provided at pediatric MS centers. It is not known how much psychosocial support is available at pediatric MS centers in the US, and this should be determined.

It is well known that funding for mental health positions in MS clinical centers is difficult, and many adults with MS who have mental health problems go untreated.<sup>34</sup> The challenges of providing mental health care in pediatric MS center may be even greater, due to the scarcity of mental health providers who have experience in this area, and the challenges of reimbursement and funding. This should not deter the pediatric MS centers and the National MS Society. They can and should play an important role in responding to the challenges of providing these services, in collaboration with the institutions which house the centers, and the staff of the centers.

### **Limitations**

This research has some limitations that must be taken into account when interpreting the results. Because of limited resources inherent in a pilot study, the sample

size is small. The small number of cases is particularly a limitation given the variety of families and circumstances involving pediatric MS. It was impossible to capture all the variation with substantial reliability given the small sample size. This suggests that we should be cautious about generalizing some of the specific findings of this study. Some of our findings describing the common experiences that affected almost all of the families we talked to are likely more reliable, however.

We have limited information about how families included in the sample differed from families who were not included in the sample. The study was conducted through the participation of two Centers which are national leaders in treating pediatric multiple sclerosis, and the families treated were mostly from New England. It is unknown how families receiving treatment outside of specialized pediatric MS centers would respond. Clearly, studies like this one need to be replicated in several geographic areas and types of treatment centers.

We guided the interview by asking a number of specific questions (see the appendix). Our choice of questions insured that we addressed a number of important topics with every family, but also structured the interview in such a way that it is difficult to assess how prominent each topic was in families' experience. Thus, for example, we asked questions about coping with the illness, about its positive impact, and about parents' concerns about the future, but it is impossible to assess accurately the relative impact of each of these topics' on families.

### **Research Directions**

Research about parents who have a child or adolescent with MS is very much at a beginning stage. The results of this study can add some direction. First, we still need to

know more about the impact of parenting a child with MS on the parents, their relationships, and their family life. Reading the transcripts of interviews for this study suggests that anxiety is a more prominent emotional experience for these parents than depression (despite Messmer-Uccelli's<sup>8</sup> findings). Words like *worried*, *frightened*, and *scared* were common, reflecting the fear that MS could harm their child in the present and in the future. It would be helpful to investigate further specific worries about pediatric MS, as it is essential that we learn how to help parents manage this long-term, reality-based anxiety over many years.

Interviewees told us that pediatric MS had an impact on their relationships with their partners, and with other family members. They said that addressing the challenges of MS sometimes strengthened a relationship, and sometimes caused further conflict in a relationship which was already troubled. From a research standpoint, we know very little about the impact of MS in a child on the parental or marital relationship, and could benefit from knowing more. Uccelli et al<sup>8</sup> found that parents of children and adolescents with MS had a lower sense of parenting competence, and were less satisfied with their parenting role than a control group. It is clear that further work in this area is warranted.

Finally, we need to know more about parents' attitudes about treatment of pediatric MS. Until recently, the disease-modifying treatments utilized with children and adolescents with MS have only had clinical trials for adults. With the positive direction taken in conducting trials with children and adolescents, and parents being asked to make difficult choices about participating in such trials, we need to know more about parents' understanding of MS, its treatment, the structure of trials, and the risks involved. One parent in the present study was reluctant to allow his child to participate in a clinical trial

because of a perceived risk of receiving a placebo. In learning how to educate parents about these trials, we can also further develop the educational process about MS for parents and families.

### **Final Words**

In addition to dealing with the difficulties of a serious illness in a child, families must contend with the reality that most people in their communities, and some in the medical community, do not realize that multiple sclerosis can affect children and adolescents. Many children and youth with MS undergo a long diagnostic odyssey before they receive a definitive diagnosis, resulting in delays receiving disease-modifying treatment. With the establishment of Pediatric MS Centers and increasing attention of the NMSS and other organizations to POMS, there is the potential for these problems to improve in the foreseeable future. Increasing research with this population is helping as well. The families in this study, and all the families treated at Pediatric MS Centers, are pioneers who are helping develop the knowledge base to improve care for children and adolescents in the future. In this spirit, we have tried to faithfully capture the voice of the parents we interviewed. We are indebted to their generous and thoughtful contributions in this study. Their courage, persistence and eloquence are powerful forces in the battle against pediatric Multiple Sclerosis.

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## Appendix 1 Parents of POMS Interview Protocol

### Instructions:

The purpose of this semi-structured interview is to help parents of pediatric MS patients describe their experience in the eight subject sections below. Although we would like to cover all eight sections, we also are looking for in-depth and thoughtful responses from the parents. With a parent who is very talkative, you may have to ask fewer questions per section, but with a parent who is giving brief answers, you will be able to ask all questions. Please ask for details and elaboration for all questions in which the response is very brief or appears to be only partially answered. Make sure the digital audio recorder is operating correctly before each interview. Words in brackets [ ...] are notes for the interviewer, and not meant to be read to the subject.

### **I. Pre-Diagnosis:**

Let's begin before MS: How were things going with your child before MS came into the picture?

What was the first symptom your child experienced that you now recognize to be related to MS?

What did you think was going on at that time?

What did the health care providers your first saw think was causing the symptoms?

What was the process like that led to the diagnosis?

### **II. Receiving the Diagnosis**

What did the doctor who gave the diagnosis say to you and your family? [About MS]

What did the doctor say you could expect in the future [prognosis]?

What was your initial reaction to hearing the diagnosis?

Did the doctor tell your child? [How did that go?]

What was **your** conversation with your child (POMS) like about the diagnosis?

How did your child react? How did your other children react?

In what ways did medical professionals respond to your needs at the time of diagnosis?

In what ways did they **not** respond to your needs?

### **III. Adapting to Life with MS**

How did you tell members of your extended family, and family friends about your child's diagnosis? [What did you say?]

What was their reaction?

Whom have you decided **not** to tell?

How did your child decide who s/he would to tell about the diagnosis?

Who did your child tell? Who did s/he not tell?

### **IV. Treatment**

How were decisions about treatment made?

Who was involved?

Were choices given by the doctor? [Referring to DMTs (disease modifying treatments)]

What was it like to start treatment with a disease modifying medication? [DMTs, not symptomatic treatment]

How have you worked out scheduling and giving medication with your child?

Who gives the medication/injection to your child?

What has been your experience with MS medication so far?

Have you felt supported by your child's healthcare team? If not, how might they be more helpful?

### **V. Family Life**

What have conversations about MS been like in your family?

What has been the impact of your child's illness on?

You? Your spouse/partner?

Has this affected your or your spouse's sleep, employment, or has it caused any social isolation for either of you?

Your other children?

Your parenting?

Your marital relationship?

Grandparents, other family members?

How has MS made family life more difficult?

How has MS strengthened your family?

### **VI. School**

What has been the reaction of teachers and school staff to your child's illness?

In what ways has the school been responsive or unresponsive to your child's needs?

Who is your contact person at your child's school for MS related issues?

How do you handle it if your child tells you s/he is not feeling well enough to go to school?

In what ways has MS affected your child's;  
Work in school? [Academic performance]  
Relationship with her/his peers?  
Participation in school activities?

## **VII. Living with MS Over Time**

What are your major concerns about your child's MS right now?

What are your major concerns about your child's MS for the future?

What has been the most difficult part of this experience?

What and whom have been most helpful to you, your family, and your child through this experience?

Have you been involved with the MS Society? Has that been helpful? Explain.  
With other families who have children with MS?  
If yes, describe.  
If not involved, why not? Would you like to be?

## **VIII. Advice to other parents**

If you were talking to the parent of a child newly diagnosed with MS, what would you tell her or him about your experience so far?

What advice would you give that parent?

What have you learned through this experience?

What might be a hopeful statement you could say to a parent of a child just diagnosed with MS?

How have you maintained hopefulness in this process?