MS *in focus*

January 2013

Young people with MS

multiple sclerosis
international federation

Multiple Sclerosis International Federation (MSIF)

MSIF's mission is to lead the global MS movement to improve the quality of life of people affected by MS, and to support better understanding and treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders.

Our objectives are to:

- Stimulate and facilitate international cooperation and collaboration in research into the understanding, treatment and cure of MS
- Support the development of effective national MS societies
- Communicate knowledge, experience and information about MS
- Advocate globally for the international MS community

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ISSN1478467x

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Letter from the Editor

For decades MS has been known as a disease that is commonly diagnosed in young adulthood. Increased knowledge and advanced technology have facilitated the process, enabling clinicians to diagnose MS very early in the disease in many cases, when a person is quite young. It is common for young people to face the challenges of MS at a point in their lives when aspirations and interests are only just being formed and developed. Health care professionals today are challenged with creating therapeutic alliances with young people who are extremely informed, empowered and who are prepared to participate in determining their treatment choices.

Depending on a person's age and culture, some aspects of living with MS will be relevant at certain times of life, such as education issues, relationships, employment or family. Teens with MS may have concerns about coping with school, as well as the transition to university or finding a job. People in their 20s and 30s may need information about managing MS in relation to a career and starting a family. Other aspects of life with MS are relevant at any age, such as their relationship with parents, self-image and disclosing MS in new relationships.

So while this edition of *MS in focus* targets adults between 18 and 35 years of age, the issues may apply to a much broader group of people depending on their personal situation and culture.

There were many topics that we felt merited discussion, thus the traditional format has been changed to permit this, and each topic is accompanied by relevant questions. We have also included an update on paediatric MS and featured some MS organisations that are running programmes or activities specifically for young people with MS.

We look forward to receiving your comments.

Michele Messmer Uccelli, Editor

Contents

The next issue of *MS in focus* will be on cognition. Please send questions and letters to michele@aism.it or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

Editorial statement

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Transition to independence

Evangeline Wassmer, Birmingham Children's Hospital, Birmingham University, UK

Like other chronic illnesses, MS can affect young adults in many ways. In addition to having a chronic illness, MS can affect a person's identity, emotional well being, relationships with peers, engagement with education and employment, and family function.

Adolescence is a time of transition and change: from being a child to an independent, mature and responsible adult, moving from school to employment, being a daughter or son to having a relationship and possibly parenthood. Having MS as a young person can add further transitions; from grief to acceptance of MS as well as moving from paediatric health care service to adult services. Transition requires adjustment and changes, some of which can be difficult.

During adolescence, the young person often realises and learns to adjust to a diagnosis of MS; that it is a chronic illness, that it will not be cured indefinitely, that the treatment is continuous, that relapses can occur at anytime, and that it can affect daily life including managing fatigue, concentration, cognition, education, future employment, friendships and family life. Adjusting to the diagnosis of MS is like a bereavement of the loss of being "fit and well", a loss of a sense of normalcy (being different to your peers) and a loss of control (symptoms can occur at any time and the long term outcome is uncertain). Parents experience a similar loss: they grieve for the hopes and dreams that they once had for their healthy child. They have to learn to accept new or adjusted dreams for their child.

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Children are often passive participants in health care. Parents take responsibility, make decisions and are the "experts". Adolescents may begin to want to take responsibility, but parents may still feel accountable. This can cause tension in a family. Parents may find themselves feeling conflict between their supervisory role and their support role, as the young person starts to manage their own health.

It is natural for young people to want independence, and they may not agree with their parents. Parents may feel anxious about handing over responsibility for health care and being excluded. Parents also know that young people tend to be oriented to the present (here and now) and are less affected by long-term health risks and therefore they may not understand the importance of regular treatment to limit future complications (for example, a relapse).

Adolescents may feel unprepared to make the transition into managing their own health care. Difficulties can occur during this time if the young person has to engage with new services (adult health care instead of paediatric health care) and sometimes there may even be a gap in care (from 16-18 years).

Health care professionals can help to empower and prepare a family. For example, helping a parent to move from providing and managing the care, to supervising and being consulted. At the same time they can help to transition the young person gradually from receiving care, to participation in care, and into managing their own health care.

Transition to adulthood is an exciting time, when young people undertake new educational, social and vocational tasks. Learning to live with the diagnosis of MS and mastering self-management is essential.

Q How can health professionals help prepare young people with MS for the transition to adult health care services?

Paediatric health care professionals can help by introducing the idea of making a transition to adult services early, to both the parents and the young person. It is a good idea to have a section of each consultation with the young person alone and ensuring it is confidential, as well as with the parents or carers. When seeing both together, clinical questions should be addressed to the young person, and should aim to ensure they understand MS, medication options and the impact MS may have on psychosocial well-being. Giving the young person a specific task, such as making the next appointment, encourages independence too.

This is a transition for both the young person and their parents, so it is important to acknowledge this to parents and to explain the challenges of letting go and allowing the young person to manage their own health. If young people and their parents can support each other and communicate well, this is likely to lead to a successful transition and an active engagement of the young person with adult services.

Q What makes routine treatment compliance difficult for young people?

Consistently taking MS treatment optimises its benefits. However, adherence to the routine often decreases over time in young people due to a number of reasons. Unique developmental changes occur in adolescence; young people gain a sense of omnipotence and may suddenly feel confident in their knowledge of the world and feel that they can do everything. But in reality they may be inexperienced, especially in assessing short and long term risk, and therefore may find it difficult to focus on the long-term benefits of taking MS medication. Adolescents may also feel that they want to be independent and have autonomy, which having dependance on carers and taking regular treatment may seem to inhibit. Other reasons for non-adherence may include forgetting to take medication, side effects, having a needle phobia, restrictions on lifestyle, unrealistic expectations of treatment (thinking it will work straight away rather than accepting that it will reduce disability in the long term). Growing into adulthood is also when young people are likely to come to terms with having a chronic disorder. This may lead to a 'bereavement' over the loss of health, with sadness, anger and denial, which may also interfere with regular treatment.

Q How can an adult carer or partner help a young person with concerns about transition?

A parent or partner is likely to understand the young person's hopes, dreams and expectations and can support them to develop a relevant and realistic treatment plan and lifestyle. A health care provider could help with this by giving the young person a check list to consider:

- I am confident in my knowledge about my condition and it's therapy
- I understand what is likely to happen with my condition when I am an adult
- I look after my own medication
- I order and collect my repeat prescriptions and book my own appointments
- I call the hospital myself if there is a query about my condition and/or therapy
- I know who, when and how to contact my health team, eg neurologist, nurse, GP
- I feel confident to be seen on my own in clinic
- I understand my rights and responsibilities to privacy, decision-making, consent and confidentiality.

Parents may also benefit from a checklist, for example that they feel confident about their child's knowledge and are able to teach their child to take responsibility for appointments and their medication plan. Also that they will encourage independence as well as understand their child's aspirations and how these may be affected by MS in the future.

Self-image

Benedetta Goretti, Department of Neurological Sciences, University of Florence, Florence, Italy

Self-esteem

Self-esteem and self-image are created by a person's judgment of their own self-worth. This evaluation is often based on how the person views the main areas of their life, including physical, mental and social day-to-day functioning. For many young people (with or without MS), self-image and self-esteem can be at risk while their bodies mature into being adults.

People with MS have consistently reported lower levels of self-esteem compared with the general population. This is not surprising given that MS-related physical disabilities can affect daily functioning.

In a recent study, social support was found to be important when considering approaches to improve self-esteem and psychological health in people with MS. Social support is a strategy that relies on a person receiving information from other people that they are loved and cared for, esteemed and valued, and part of a network of communication and mutual obligation or help.

Body image and sexual function

Beyond the involvement of self-esteem, chronic health conditions, including MS, are frequently associated with impaired body image and sexual dysfunction, which are often under-reported and under-diagnosed.

The concept of body image includes, among others, conscious experiences and inner representation of the body, along with an individual's feelings about their body and its function.

It has been observed that even people with mild MS symptoms, and who are not considered depressed, still have to deal with problems of body image, in particular their attractiveness, sexuality and fears about physical disabilities.

Body image problems should be addressed when people with MS meet their doctor or MS nurse, taking into account gender-specific differences. If necessary, individuals should be encouraged to seek and accept psychological help.

Sexual functioning is a complex process that depends on the neurological, vascular and endocrine systems of the body, and is influenced by numerous psychosocial factors, including family, religious background or sexual partner, as well as individual factors such as self-esteem or self-image. Young people with MS may feel that their sexual problems are not important enough to be raised when they see their doctor, and doctors may feel uncomfortable or under-prepared to deal with them.

With the emerging awareness of the importance of sexual function on quality of life, and the development of effective medical and psychosexual

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Q Since my diagnosis, whenever I look in the mirror, I feel like I'm not the same person anymore and that the disease has made me unattractive. My self-esteem is really low and is affecting my relationship with my boyfriend. Do you have any advice?

It is common for a person's perception of themselves to change when something big changes in their life, such as being diagnosed with MS. One practical suggestion is to make a list of the things you like about yourself and also what you think the people around you like. You could ask your boyfriend to do the same thing – it is likely that most of the things he writes down will not be related to your appearance. Then, when you are feeling low, you can look at the list to help remind yourself that you are still the same you.

Q When I'm fatigued I have trouble holding my arms up for long enough to do my hair and make-up. I don't mind day-to-day, but I'm going to a wedding soon and I want to look my best. Do you have any ideas? I can't afford to go to a beauty salon.

If you live near a department store, you can often book in for a free make-up 'trial' – see if you can book one of these for the day of the wedding. If you know other women going to the wedding, you could invite them all to meet at your house beforehand, and ask them to help you to do your hair and make-up. The good thing about weddings is that it is the bride who will be getting most of the attention so just keep it simple.

Q I have bad ataxia as part of my MS and when I go out with my friends I feel like people are staring at me. What can I do?

Unfortunately it is human nature to notice differences in people. However, most look for a few seconds and then carry on with their own lives, so try not to let it distract you from what you are doing. Instead, focus on your friends and what you like doing together – it is likely that they are not bothered by your ataxia and they are the people that count.

Q I've been having erection problems recently due to MS and now I think my partner is avoiding intimacy. I'm not sure what to do.

Firstly, it is important to raise this with your MS nurse or neurologist when you next see them, so you can discuss treatment options. Sexual problems can be difficult for couples to talk about, but it is important to communicate with each other and to try to find alternative solutions. Partners of people with MS sometimes feel worried about initiating intimacy in case the person with MS is fatigued, or they worry that they might hurt them if they have MS pain. Communicating is not always easy, but it can really help.

treatments for sexual problems, it is no longer acceptable to ignore sexual difficulties of people with neurological diseases like MS. Moreover, sexual problems may interfere with family planning and fertility.

The assessment and treatment of any sexual problems should combine medical and psycho-sexual approaches and be part of general disease monitoring and checkups. Heath care professionals can help by validating that young people with MS have sexual needs, by providing education and information to young people with MS, by allowing and encouraging people with MS to express their difficulties, and also by referring them to specialists and other information resources.

Relationships and disclosing MS

Rosalind Kalb, PhD, National MS Society, New York, USA

Introduction

Making connections with others, forming new relationships and eventually finding a life partner, are all high on the priority list for young adults. Relationships are often the most rewarding and satisfying aspect of our lives, yet they can be challenging to develop, nourish and sustain. Women and men living with MS often worry that MS will add to these challenges – making it difficult for them to meet people and find partners who value them in spite of their MS, and are willing to share the complexities of an unpredictable, chronic illness.

But like all young adults, people with MS do have successful relationships, find life partners and enjoy family life. The following strategies can help people navigate some of the challenges along the way – particularly those related to disclosing their diagnosis to people they are meeting or with whom they are in a new relationship with, and to communicating more effectively about MS-related issues in their ongoing relationships.

New relationships

- How people feel about themselves and their MS will determine, in large part, how they present themselves to others. Remembering that people “are more than their MS,” and that MS is only a small part of who they are, will make it easier for people they are dating to know and enjoy the other parts of them as well.
- The first date is a time for two people to decide whether they want to see each other again. There is no need to share personal information (about MS or anything else) unless one chooses to do so.
- Once it feels as though the relationship is worth pursuing, it is time for both people to begin sharing important health and personal information about themselves. Everyone has something they worry about telling a prospective partner; when one person shares, it encourages the other person to do so as well.
- Healthy relationships are usually built on honesty, good communication and trust. Secrets and half-truths do not make a strong foundation for success.
- While some people will be reluctant to pursue a relationship with someone who has MS, other people will not.
- When disclosing the diagnosis, it is important to give the other person time and space to think about it and respond. They are likely to have questions and concerns that need to be shared and discussed.

Ongoing relationships

- When one person in a relationship has MS, both people are living with it – and each has to grieve over the changes and losses it can bring, and learn to manage the challenges.
- Understanding MS – the symptoms it can cause and strategies for managing them – is essential for both members of the couple.
- Everyone handles challenges differently. It is important to recognise and respect each other’s ways of coping.
- Open communication is one important key to success. No matter how much two people love each other, they cannot read each other’s minds.
- Healthy communication leads to shared problem-solving, which cuts down on competition over who is more stressed or overwhelmed, and leads to more effective solutions for both members of the couple.

In conclusion, there are many strategies that can help young people with MS form and maintain loving relationships, whether they are single, in a short-term or a long-term relationship. Much of this relies on good, honest communication between all the parties involved. For young people with MS it is also about identifying when they are ready to discuss their MS and how much they want to share.

Q How do I know when it's the right time to tell someone I am dating that I have MS?

No time is right for everyone. It may help to ask yourself when you would like to know important information about the other person. If you are invested enough in the relationship to want to know about his or her health or other issues, that may be the perfect time to share your diagnosis.

Q How do I know whether I'm talking too much about my MS to others or too little?

Remembering that MS is only a part of who you are may help answer the question. Someone who cares about you will certainly want to know about your MS and how you are feeling, but will quickly get bored if that is the only subject of conversation. On the other hand, withholding important information about how you are feeling or challenges you are facing puts other people in the position of having to guess, which is likely to leave you both feeling pretty frustrated. A good strategy is to ask yourself if you spend as much time talking about the other person and issues of shared interest, as you do talking about your MS.

Q Why would anyone want to get involved with a person who has a chronic, unpredictable illness like MS?

Because getting diagnosed with MS is never something a person chooses, it is hard to imagine another person making the choice to take on its challenges. But remember that you have a lot more to offer someone than your MS. When people fall in love, they share interests, beliefs, sexual attraction, joys, sorrows and challenges, with MS just being one part of the package.

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Q What are the best ways to go about meeting people when you have an illness or disability?

Again, no single answer is right for everyone and the answer is likely to depend on how and where you feel most comfortable. You may look for opportunities to meet people who share your interests and passions, such as classes or clubs. Or you may feel more comfortable in groups where others have MS and may identify more closely with your issues and challenges. In recent years, many young people have opted to get to know others through online dating sites or social networking sites. These online venues offer people the opportunity to share information about themselves in whatever way feels most comfortable, and to select the responses that seem like the best fit for them. Many people with MS have found life partners in this way. The social networking sites of MS organisations and societies also offer opportunities to make friendships and find peer support.

Education

James Bailey, UK MS Society, London, UK

School, college or university can present many challenges for young people with MS, but with some adjustment and the right support, many find ways to keep up with their studies and their social lives.

University can bring its own challenges, excitement and opportunities – including gaining a new independence, balancing student life with studies, thinking about finances, and building a new social scene. For any student this can be a life-changing time, and many people – with and without MS – thrive in this environment. Young people with MS may need to seek some support – many universities have specific support for people with disabilities, and in some countries, this is referred to as a disability liaison officer.

Adjustments for study

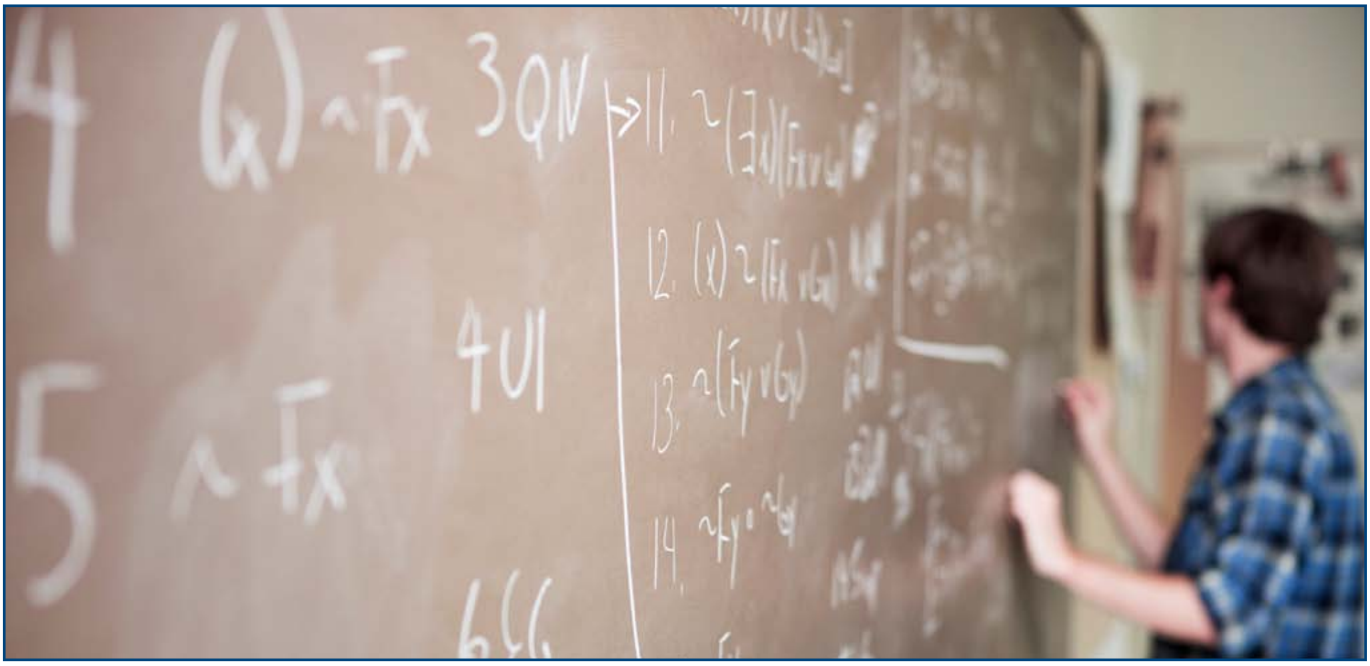
Young people are expected to study in a fairly fast-paced environment, which can have many distractions. The symptoms of MS can make this particularly difficult. Some people with MS find it hard to recall facts quickly, or to change concentration from one thing to another. Other symptoms, such as fatigue or problems with vision, can equally affect their learning.

A flexible and understanding school or university can make a large difference – for example, allowing a student to adjust their timetable to help to avoid fatigue in the afternoon, allowing flexible deadlines for assignments, or the use of a laptop or tape recorder if handwriting is difficult.

There may be times when a young person needs to take time off because of their MS. Schools or universities can help ensure this does not cause the young person to get behind by keeping the student up to date with the learning programme in their absence. It may also be necessary for there to be a gradual return to full-time study.

Educating the educators

Some education institutions are very good at providing help and being flexible, but this is not



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always the case. Even the most helpful teachers or lecturers may not have taught anyone else with MS, so young people and their families may find they spend time educating the school or university about MS.

Information from MS organisations can be useful, but it is also important that the school understands how MS affects that particular young person, and how to manage if things change. Health or social care professionals can often help to explain what MS is, and to be a point of contact between the young person, their family and the school or university. Good communication between all parties is important.

Telling friends and teachers

If a young person feels they can be open and communicative about the difficulties they experience with MS, this might help them avoid misunderstandings. For example, without an explanation, others might see signs of fatigue as boredom or rudeness.

But how much a young person wants to share about their MS with their friends or their school or university will be very individual. It is important for those around them to respect the young person's privacy. Just like an adult in the workplace, a student with MS might not want to share their diagnosis or details of their MS with the whole school or university. A young person with MS might feel particularly wary or vulnerable, so it is important they feel they can trust the people around them.

Living with MS, going to school or university and growing up all at the same time is a lot to take on. Families, friends, schools and health care professionals can all offer help and support to young people with MS. But sometimes a young person would rather talk to an MS or youth organisation. Through these, they are also likely to find peer support and be able to share experiences with others in a similar situation.

Q I'm a university lecturer. A student told me that she has MS and that she may miss class occasionally due to her therapy schedule. I am interested in knowing more about the disease and I've read on the internet that there are many strategies that can help a young person with MS manage education. How can I help?

It is true that there are many strategies that can help a young person with MS at university. Above all, it is important to respect the privacy of the individual. In this specific case, the young woman disclosed her diagnosis in order to advise you of eventual absences. Since she did not make any specific requests (such as adaptation to her schedule, use of recording equipment in the classroom, or extra time for completing assignments or tests), it may not be appropriate to approach her with an offer of help, when she may not need it. The best strategy is to be informed so that you can be prepared for any request she may have in the future.

Q I am considering accepting a place at a university but feel unsure because of my mobility and fatigue problems. A friend suggested that I consult the university's Disability Liaison Officer – what kind of help do they offer?

This is a common concern for many young people with MS. If the university you are considering has a Disability Liaison Officer this could be a useful point of contact and advice. They should be able to meet with you to discuss possible solutions, such as accessible access to buildings, ensuring that your tutorials and lectures take place in accessible rooms and are not far apart, and providing note-taking services if this would be useful.

They may also be available to liaise with academic and administrative staff at the university if you require extensions on assignments or alternative exam arrangements. Usefully, they will also know about the university's general policies and procedures.

Career issues

Alessia Villani, Advocacy Programme, Italian MS Society, Genoa, Italy

It is common for a young person diagnosed with MS to experience doubts about the future. Many may question whether or not they will be forced to give up their dreams and aspirations. Entering the job market after completing secondary school or university is not easy for any young person, especially considering today's economic climate. Having MS can make it all the more challenging.

One important decision a young person with MS looking for a job faces is whether or not to disclose their diagnosis at the time of the interview. This may be an issue for those who are already employed at the time of receiving the diagnosis as well. Countries have different policies on a person's legal obligation to disclose their diagnosis to a potential or current employer. In many countries, an employed person is not obligated to provide information to their employer regarding their health, although there may be risks for not doing so, particularly in countries where private health insurance is supplied through employers.

There are various reasons that motivate a person not to disclose the fact that they have MS. The most common reasons include a fear of the reaction of others in the workplace and the person's fear that they are putting their employment status at risk, even in countries where there is legislation in place that should protect people with MS from being targets of discrimination.

Some people with MS have reported that not disclosing the diagnosis can be the cause of significant stress in the workplace, particularly when symptoms become more evident or when time off work is needed due to adverse effects of therapy, periods of worsening symptoms, doctor's visits or other MS-related needs.

For many young people, it may be the case that symptoms are "invisible" and do not impact on their ability to carry out job responsibilities or do not require particular workplace adjustments. Often in this type of situation the decision not to disclose

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the diagnosis can be a valid one, although, as MS is an unpredictable disease, the decision may require revisiting at a later time.

It is very important for young people with MS to be informed about the employment-related rights that exist in their country. Many MS organisations and other organisations have employment services that can assist the person with addressing more practical issues, such as preparing for a job interview, writing a resume and even assessing accessibility issues to and within the workplace. Being in gainful employment, contributing to society and performing a job that is personally satisfying are factors that are linked to a positive self-image, confidence and having a sense of purpose to one's life. MS does not mean that a young person has to sacrifice his or her aspirations. Being informed about MS and about employment rights, as well as having support at various stages of the work cycle, are the foundation for successfully finding and maintaining employment, despite a diagnosis of MS.

Q I am very fatigued. How do I explain it to my employer without seeming lazy?

It is important that your employer is aware of your diagnosis. If this is the case, you should ask for time to speak with him or her privately in order to explain any symptoms you experience, particularly fatigue, which certainly can influence work. It is important to underline that fatigue is a recognised symptom of MS and that it is invisible to others and very commonly misinterpreted as a lack of motivation or laziness. Some MS organisations provide written materials that can help you in explaining how fatigue can influence your daily functioning. In many countries a certificate from a specialist (such as a neurologist) can assure that your requests and needs are met in the workplace.

Q My boss is sympathetic to my condition but has changed my responsibilities and now my job is so simple I feel I am not using all my experience and I am bored.

It may be that your employer has decreased your level of responsibilities thinking that he or she is helping you to avoid too much stress or perhaps for fear that your workload could somehow worsen your symptoms. In any case, if you feel that you are working under your level of experience or capabilities, the best approach is to speak directly to your employer, explaining the fact that you do feel capable of facing more challenging work than you are currently doing. It is important to express any flexibility you may need, based on the symptoms you experience.

Q I was planning on studying accounting, but now that I've been diagnosed with MS should I change my career choice?

Being diagnosed with MS does not mean giving up on your plans for the future. Accounting or any challenging career is not necessarily incompatible with having MS. However, because MS is unpredictable, and no one can know exactly which symptoms will manifest with what intensity, and at what point of the disease course, it is important to be realistic in acknowledging that symptoms such as fatigue and mild cognitive deficits are not uncommon in MS and can influence employment. Having a network of support that includes health care professionals knowledgeable in your disease will help you face the challenges of MS in whatever career you decide to pursue.

Considerations when starting a family

Gary Fulcher, MS Australia, Sydney, Australia

Thinking ahead is an important part of deciding to become parents, particularly for people living with MS. This article provides information about some of the issues that most concern people with MS about starting a family.

Relationships

MS can bring changes that may strain even the strongest relationships, including experiencing the trauma and emotional distress of a diagnosis of MS. MS-related symptoms and financial difficulties can add to the pressure. As all couples planning a family should be emotionally ready to take this step, it is important to seek help if these issues are or become a problem.

Financial concerns

Certain aspects of the disease may affect a person's ability to work. The partner may also need to take time off work to provide care for the person with MS and/or their child. It is necessary to check what supports exist locally to help couples maintain employment or gain financial assistance.

The likelihood of a child developing MS is indicated in the following statistics:

Out of 1,000 people:	Percentage risk
• 1 person on average will develop MS in their lifetime	• 0.1%
• 30-50 people will develop MS if one parent has MS*	• 3-5%
• 120 people if both parents have MS	• 12%
• 880 people will NOT get MS even if both parents have MS	• -88%

*The risk is higher if the mother is the parent with MS.

Ability to look after children in the future

Because MS is so unpredictable, there is no straightforward answer to whether a person with MS will have the ability to look after a child in the future. Generally, many people with MS experience some level of disability within 10 years of disease onset; however, most maintain physical independence for 25 years and more after diagnosis.

Role changes within the family

Over the course of MS, a shift in roles may be necessary and this can occur unexpectedly. The person with MS can go from being the main contributor in the household to needing care. There may be times when a partner may need to take on the role of caregiver and parent, and this can cause stress for the family.

Mood and emotions

For some people, worries about having or coping with a child can make anxiety or depression worse, while for others the worry of not having a family causes distress. For those with children, parenting can create stress and make managing MS harder. Each person is different, so it is important for couples to consider their feelings about how they will cope with their decision to have a child or not.

Pregnancy and MS

Pregnancy does not affect the long-term course of the disease. Many women with MS have fewer relapses during pregnancy, especially during the second and third trimester. This is thought to be caused by pregnancy hormones dampening the activity of the immune system. However, relapses can still occur and can be a challenge which may need to be treated.

Mothers are more likely to experience a relapse in the three months after the birth. Research shows that pregnancy and delivery, epidurals or after-birth relapses do not have any impact on a woman's level of ability in the long-term.

Breastfeeding

Breastfeeding does not increase relapse rate or lead to a loss of ability. In fact, exclusive breastfeeding may even have a protective effect for the mother against MS activity.

Mothers with more active MS often choose not to breastfeed and return to treatment immediately. Bottle feeding also allows both parents to share night feeding, which may help when fatigue is an issue. Neurologists and other health care providers can give individually tailored advice.

Breastfeeding can bestow a protective effect on children against developing MS (as well as other autoimmune diseases) providing the period of breastfeeding exceeds four months.

A full version of this article appears on our website at www.msif.org/startingafamily

Q Does MS affect fertility?

Unfortunately, little research is available about fertility in MS. On the basis of the existing evidence it can be concluded that, for women, MS does not generally affect fertility. It is important, however, to be well-informed about any effects of medications for MS on fertility. Fertility treatment, specifically hormone stimulation for pregnancy (for example, IVF) has been shown to increase relapse rates in a small group of women with MS. Seek advice from neurologists and advising gynaecologists when considering this approach. For men, MS may affect fertility. It has been suggested that endocrine abnormalities may impair sex hormone levels. This area of research must be studied further in order to understand the mechanisms causing this malfunction. Further, about two thirds of men with MS experience erectile dysfunction, often caused by demyelination. Men with MS should seek medical advice about fertility issues and timing if they want to start a family.

Q What about my medications before and during pregnancy?

For men, the main issue about medications is whether they affect fertility and should be avoided or reduced if couples are trying to conceive. The very sparse research suggests that none of the standard disease modifying drugs have significant effects on male fertility. Some more radical drug treatments, such as cyclophosphamide, do have impacts on fertility for both genders and it is always worth seeking medical advice when planning to start or extend a family. For women, a neurologist may recommend stopping medication 1-3 months before trying to conceive and not using medication during pregnancy or while breastfeeding. Some medications for MS have been detected in breast milk and, therefore, speaking to a neurologist about breastfeeding before re-commencing medications for MS is recommended.

Interferon beta-1a or 1b and glatiramer acetate: there is not enough information about the full effects of these medications on the baby. Therefore, continued use in pregnancy is not recommended.
Cladribine, fingolimod and natalizumab: there are no studies involving this drug and pregnant women.
Steroids (such as prednisone and methylprednisolone): these drugs have been taken by a large number of pregnant women without causing direct or indirect harmful effects on the foetus. However, as a precaution, these drugs should be avoided during pregnancy and breastfeeding unless your neurologist specifically advises otherwise.

Q Will MS affect my baby during pregnancy?

Having MS does not increase the chance of having a miscarriage or still-born child or increase the number of infant deaths or foetal abnormalities. Therefore, MS itself does not pose a risk to the mother or child.

Living a healthy lifestyle

Matt Plow, Department of Physical Medicine and Rehabilitation, Cleveland Clinic Lerner Research Institute, Cleveland, Ohio, USA

As a young adult with MS, it is important to develop healthy lifestyle habits for general wellbeing and also to prevent secondary complications of MS. We know from research that inactivity, unhealthy eating habits and chronic stress, or using poor coping strategies to reduce stress, can eventually have adverse effects on MS. Developing healthy habits that facilitate wellness as a young adult may help in coping with MS in the future.

According to the World Health Organization, "health is a state of physical, mental, and social wellbeing and not merely the absence of disease". Wellness refers to the positive aspect of health and is the capacity to obtain pleasure from life and to overcome obstacles or barriers. With all the unhealthy temptations in some cultures, it is hard enough to engage in behaviours that facilitate wellness as it is, let alone when presented with MS symptoms acting as additional barriers.

Deciding to live a healthy lifestyle is an on-going process and consists, in part, in finding the right balance in one's life roles (for example, a balance between work and play). It is not just a matter of will-power and determination; it is learning the necessary skills to overcome barriers, developing a supportive social environment, and creating habits that make engaging in healthy behaviours seem natural. Healthy behaviours, such as engaging in physical activity, making good food choices or utilising strategies to manage stress, often do not have immediate rewards. This can make unhealthy activities that have instant-gratification more enticing.

Making healthy changes

It is important to identify areas of life to improve and subsequently to take action. It is helpful to think about rewards of engaging in the behaviour, set specific and measurable goals, generate an action plan (such as how, when, where and anticipating barriers), keep a daily log, enlist support from family and friends and have tangible rewards for meeting goals.

Finding benefits that are meaningful for each person (for example, improved physical fitness, weight loss, decreased fatigue, etc) is also important. Once someone is convinced of the benefits of wellness and decides to take action, a review of a typical day is helpful in order to set measurable goals and develop a plan to achieve those goals. A person with MS might consider the types of activities they like to do in the afternoon and evening after school or work, for example playing video games or watching television. Research suggests that playing interactive video games, such as Nintendo Wii Fit™, can be beneficial for people with MS as a low-impact physical activity.

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Managing stress

Another important life area to think about as a young adult with MS is stress and coping with stress. Stress can affect all aspects of life and developing good stress management habits now can prevent many health problems later in life.

Having a chronic disease that has an unpredictable course can add to stress. Engaging in physical activity, talking to family, friends or a healthcare provider, utilising relaxation techniques, such as meditation and imagery, and finding ways to manage time efficiently are productive ways to deal with stress. Over-eating, watching television or playing videogames for hours, smoking, drinking too much, always blaming others and procrastinating may temporarily reduce stress, but these unhealthy habits have long-term consequences.

Learning productive ways to manage stress, and getting the right balance between work and leisure activities, can help young people with MS cope with the disease. Identifying and reducing any barriers to healthy living makes it easier to engage in healthy behaviours that facilitate wellness.

Q I think there are aspects of my lifestyle that are unhealthy - how can I identify and change these?

Firstly, ask yourself what you do day-to-day that might be affecting your wellness. For example, stress at work, unhealthy habits like smoking, abusing alcohol or other substances, lack of exercise or poor eating habits. Then make a list of ways to encourage a change in these behaviours, for example finding information about their effects from reliable non-profit or MS organisation websites, asking family and friends for support (especially someone you are close to and who understands your lifestyle), and planning alternatives with health care professionals such as an MS nurse, doctor or anyone else involved in your care. Aim for a balanced lifestyle, including social and physical activities for emotional (humour is very good for us all) and physical wellbeing.

Q I want to focus on being healthy to improve my wellness with MS. What should my first steps be?

Firstly you could try to identify areas of your life which already give you positive feelings of wellness, such as socialising with friends, exercising or spending time with your children, and try to ensure you prioritise these activities day-to-day. For the unhealthy behaviours, such as a poor diet or lack of exercise, set small, attainable goals rather than large ones, and make sure you reward yourself for achieving them. This could be developed into an action plan that includes enlisting the support of health care providers, family, friends or roommates and you could record your progress and achievements in a journal.

Q How can I enlist 'keeping healthy' support from friends and family to help me stay focussed?

Peer support is important in any lifestyle change and it may be a good idea to be selective about who you ask – try involving people who are positive about your plans and who value the new lifestyle behaviours you are focussing on. If you have joined an exercise class, making a new friend there who shares your goals will help keep you motivated.

If your family doesn't cooperate with – or even seems to sabotage – your healthy living efforts, tell them how important your health is to you, and how important their health is to you as well. Having small shared goals could be fun and motivational for each other.

Be proactive – schedule a morning catch-up over coffee or a walk with a friend instead of going out late, and explain that this will reduce the symptom of MS fatigue.

Approaching pharmacological treatment as a young person with MS

Kitty Harrison, International Organization of MS Nurses, Utrecht, The Netherlands

Today there are a number of different treatment options available for people with MS, including immunomodulating therapies, immunosuppressive therapies and symptomatic treatments. Treatment that is able to modify the disease (often called disease-modifying treatment) is typically initiated at the earliest possible stage in the disease process in order to prevent inflammation and to minimise axonal loss. This means that many people are starting MS treatment as young adults.

Being informed

For most young people diagnosed with MS, the internet is the first place to look for information about therapy options. While there is a great deal of valid information available, there is also a lot of information that may seem very convincing, but lacks scientific evidence. Health care providers have the role of supporting the individual in sorting through all of the information that is available on therapies, and providing comprehensive information where it is lacking, about all available options.

Shared decision-making

Young people with MS need to communicate effectively with their health care providers in order to make sure their values, needs and treatment expectations are understood. On the other hand, health care providers also have the role of supporting the young person by providing information about the risks and benefits of various treatments, understanding an individual's values and ultimately facilitating treatment decisions.

When new therapies become available, health care professionals are faced with the important task of clarifying expectations, helping young people to understand the rationale for continuing on their current regimen or whether switching to a new therapy is appropriate. Through the development of a good relationship with the health care provider, a young person is able to appraise how they are doing on their current treatment and then weigh the evidence of something new in light of their disease course and information available from the media and from peers.

Having a health care professional one can trust, receiving adequate information, having realistic and informed expectations of treatment are all aspects that support adherence to therapy.

Making symptomatic therapy choices

While the decision of when and which disease-modifying therapy is a relevant one, for many young people with MS, a careful and informed decision regarding symptomatic therapies is also important. Unfortunately, many MS symptoms are difficult to evaluate, difficult to describe and they may not have effective therapies available. In many countries, symptomatic therapies that are helpful for some symptoms, but not specifically approved for MS, may also have a significant cost.

Another issue in symptom management is the fact that a number of pharmacological therapies have side effects that many young people may find intolerable, particularly if they interfere with work or studying. Some symptomatic treatment can make other MS symptoms worse. In this case a critical evaluation of the risks and benefits is important. All of these aspects require information and access to a health care provider who is competent in MS and who can accompany the young person in making treatment choices that are compatible with their lifestyle and priorities.

Q I feel like I have the flu every time I take my MS medication – I don’t feel like going out with friends and it’s hard to get to university when I feel like this.

Flu-like symptoms are common during the start of disease-modifying therapy, particularly fever. Strategies that might help are planning the timing of injections around your social life, work or school schedule, and using paracetamol (acetaminophen) to help reduce flu-like symptoms.

Q I have red swollen areas from injecting in my arms and legs and I felt really self-conscious about anyone seeing my limbs this summer. I’m still doing the same therapy, but I don’t know if I’ll keep injecting when summer comes around again. Is there anything that can help reduce this embarrassing side effect?

Injection site reactions are common and can have a negative impact on a young person’s body image. There are strategies that will help such as the rotation of the injection site and the use of an auto-injector. Training and support by a health care provider, and written or video information about injection techniques, may help too. Switching to another therapy may reduce site reactions, but this needs to be discussed with a neurologist or MS nurse. Many pharmaceutical companies also provide helpful information about managing the side effects of these medications.

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Children with MS

Sona Narula, Amy Waldman, and Brenda Banwell, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA

Although MS is typically thought of as a disease of adults, approximately 3-5 percent of all people with MS experience their first clinical symptom in childhood. As clinicians have become more familiar with identifying and diagnosing MS in children, researchers have focused more attention on the different distinguishing features of paediatric and adult-onset MS. In addition, as children with MS experience clinical symptoms closer in time to a triggering event or exposure, a better understanding of the pathogenesis and aetiologies of MS may be gained by studying and following children with MS over time.

Diagnosing MS in children

The criteria used to diagnose MS in children requires a demonstration of central nervous system inflammation that is separated in both time and space (ie, inflammation at different times in two different parts of the central nervous system).

It is imperative that other disorders that may mimic MS (for example, lupus, small-vessel vasculitis, Neuromyelitis Optica (NMO), Acute Disseminated Encephalomyelitis (ADEM), infection or metabolic disorders) be excluded. A diagnosis of MS should be questioned in any child who experiences attacks consistently associated with encephalopathy, demonstrates a progressive course from onset, has evidence of peripheral nervous system involvement, or demonstrates features such as persistent fever, headache, organ dysfunction or severe psychiatric symptoms.

Diagnosing a child with MS can be challenging as subtle neurologic symptoms are often difficult to identify in young children. For instance, as compared with adults, sensory and visual symptoms may be difficult for children to describe and may not be brought to the attention of a parent or care provider unless they are severe or impacting the child's daily functioning.

In addition, while ADEM is clinically separate from MS, it is sometimes difficult to initially separate the two entities in young children. ADEM is an acute, typically single phase, demyelinating event that generally follows an illness or vaccination and is clinically characterised by many neurologic symptoms, encephalopathy and large, ill-defined lesions on MRI. Although about 5-18 percent of children with ADEM will eventually be diagnosed with MS, these individuals must exhibit two further demyelinating events that are not secondary to ADEM before they meet diagnostic criteria for MS.

What have we learned about paediatric MS?

More than 98 percent of children with MS will have the relapsing-remitting form. The relapse rate in the first few years from onset is higher in children with MS as compared to adults with MS and more than 75 percent of children will experience their second clinical attack within a year of their first demyelinating event.

Although children do experience more attacks, their recovery is generally excellent. Progressive accrual of physical disability unrelated to relapses (secondary progressive MS) occurs rarely during childhood, but has been reported to develop approximately 20 years after the first attack in 50 percent of children with MS. Although this reflects a longer time to physical disability, the age at which children with MS reach significant disability is generally younger than people with adult-onset MS. Paediatric-onset MS is more common in girls after the age of 12 years, while in younger children, the ratio of boys to girls is equal. The MRI features of MS in

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children do differ in important ways from the lesion patterns in adults. Children with MS onset before they are 12 years old have a tendency to have larger, ill-defined lesions that may resolve. Over time, as the child matures, the lesion pattern tends to demonstrate features more typical of adult-onset MS. Additionally, there tends to be more lesions in the brain stem and cerebellar areas in early-onset MS than is typically seen in the adult-onset form of the disease. Further, cerebrospinal fluid studies in children are different to adults, which may reflect an immaturity of their immune system response.

More than half of children with MS report significant fatigue, depression and cognitive impairment within a few years of diagnosis. As these problems can affect school performance and quality of life, it is imperative that these aspects are fully evaluated, monitored and treated and that support at school is offered.

What do we still need to learn?

There are currently multiple therapies that have been approved for the prevention of relapses in relapsing-remitting MS in adults, but to date, there have been no randomised controlled trials of these therapies for children with MS. All of the efficacy and safety data for the paediatric cohort has come from retrospective studies, open label observational studies and case reports.

Given the now widespread acceptance of the current disease-modifying therapies for relapsing-remitting MS in adults, it is unlikely that large-scale clinical trials of any of these agents will be tested on children with MS. Clinical trials of new agents, however, are mandated by the European Medicines Agency and the US Federal Drug Agency and paediatric investigation plans for these new therapies are under consideration.

As fatigue and cognitive impairment are extremely significant issues for children with MS, interventions are now being designed and tested in this population. Examples of interventions include cognitive rehabilitation and exercise programmes that are designed to improve fatigue, mood and ultimately quality of life.

With more children being diagnosed with MS, greater awareness of the multidisciplinary needs of this population should be addressed. For instance, as fatigue may limit a child's ability to attend school full-time, or mobility problems may limit the child's ability to walk in busy hallways, supports should be discussed with the school and educational plans should be tailored for each child.

In addition to the efficacy of disease-modifying therapies, adherence is another significant issue that may influence the treatment effect for children with MS. As a result, family support should be offered to both parents and children to help with the acceptance of a new diagnosis and to reinforce the need for treatment if a preventative medication is advised. Additionally, peer support is essential and may improve both adherence and quality of life.

Finally, paediatric-onset MS remains a rare disease. Collaboration between clinicians and researchers will be essential to develop high-quality treatment plans, to ensure the safe and effective application of new therapies for the paediatric MS population, and to further explore the aetiology and immune responses that characterises MS in childhood.

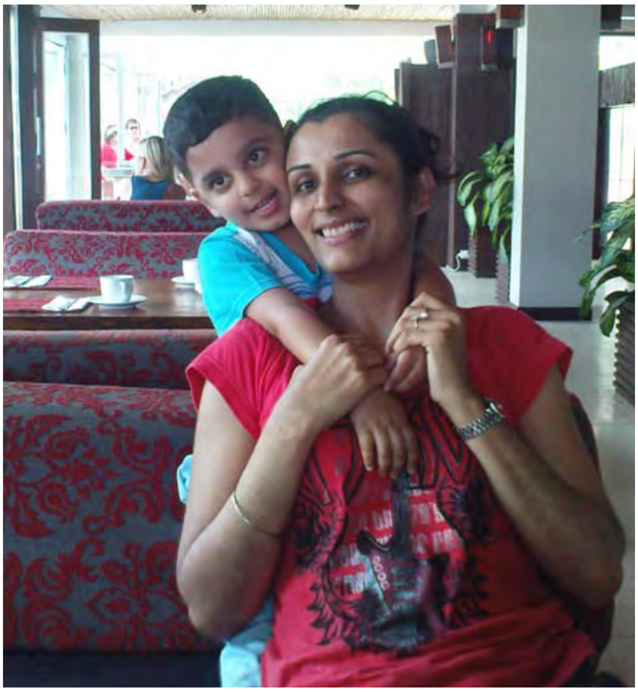
The International Pediatric Multiple Sclerosis Study Group (www.ipmssg.org), which is supported by MSIF, and has more than 150 members from over 40 countries, aims to assist in the achievement of these goals.

Young people from Malaysia and Canada share their stories of MS

Keshvinder, Malaysia

I am 35 and of Sikh origin. I live in an apartment in Subang Jaya, Malaysia, with my husband and son. I worked as an air stewardess with Malaysia Airlines for five years until I was diagnosed with MS, after which they asked me to leave. For the last seven years I have been praying and looking after my son.

I experienced my first symptoms a week after my wedding, when I was working. I had back pain, heaviness in my left leg, a tingling feeling in my arms and legs, numbness, and a loss of sensation and balance. By the time I came home, I could hardly walk. After an MRI and three doses of methyprednisolone drips I recovered, but I never felt the same again. My leg remained numb. I was diagnosed in 2004 when I was 27 and had the symptoms again – I went for another MRI and a new lesion was found. At the time, I did not take it very seriously, I always thought that I would be OK, but I was ignorant. My husband and I kept it to ourselves and didn't tell our families.



I have been getting at least two attacks a year since I was diagnosed. I always recover but I am never the same. I can no longer dance (my greatest passion) and, since 2011, I have been in a wheelchair and am basically paralysed from the stomach downwards. I was very angry for a while because I hadn't taken the disease seriously, but now I'm proud of my independence. I dress myself, transfer myself from chair to bed, cook, shower my son – basically everything I need to do at home.

Over the years, MS has caused a strain on my marriage. We have been sexually inactive for a long time, even before I used a wheelchair. My husband still helps me in a practical way, but not with emotional support.

My son is very active and I get frustrated that I can't run around with him, or go swimming or play sport. My greatest companion is God.

The main problems for people with MS in Malaysia are acceptance of the illness and the perception of other people. They think that we are lazy and making excuses. Most places are not wheelchair friendly – if you see someone in a wheelchair here it's like seeing an alien. Support from family and friends is therefore really important, and it is good to be involved in organisations like the MS Association of Malaysia (www.msmalaysia.com.my). People with MS can get together and share their feelings.

My advice to people with MS is to seek medical treatment as soon as possible. In Malaysia we have a big problem with people seeking a bomoh (a "witch doctor") rather than a doctor because they think some black magic has befallen on them. Also, try to remember, our life has come to a comma, not a full stop. Don't let anything dampen you or pull you down, stay positive, happy and believe in God.

Adam, Canada

I am the youngest of five children. I was born and raised in Mississauga, Ontario, Canada and love living in my city. I live with my parents and I'm going back to college in the winter, so at the moment I am looking for a summer job and hanging out with my buddies.

I was diagnosed with MS when I was 16 (I'm 20 now) and my main symptoms are balance problems, fatigue, tremor in my hands and weakness in my legs. Of all my symptoms, balance and leg weakness are my biggest problems. This is because I can only walk for 15 minutes on a good day, but 5-10 minutes on a bad day. My symptoms make me walk like I'm drunk, and I don't even drink alcohol. Just got to laugh about it I guess.

Believe it or not, I didn't take my diagnosis too badly at first. I'm really optimistic, so when I stopped walking, I told myself "you're going to start walking again, don't stress". But then later I started to realise that I have this thing for the rest of my life. Sticking a needle in myself every day, going to MRIs, living with the symptoms and having relapses finally started to weigh me down.

One thing I am very grateful for is my friends and family. They have been there for me since day one and always give me support when I need it. They don't even care about the way I walk – my friends always understand when I need a break and they sit right beside me.

MS completely changed my life; it got real. I used to play a lot of basketball and football with my friends and, because of MS, I can't play the way I used to. Sometimes I am late to class because I walk slowly but my teachers understand. My fatigue and leg weakness get in the way of going to parties or clubs with my friends which I miss a lot. Before I begin any sort of relationship with someone, I tell them about my MS. Those who matter won't care, and those who do care don't matter. As long as I am happy, try to stay healthy, keep a tight circle of loyal, supportive people and am not letting my MS bring me down, then I will always be happy. My plans for the future include hoping to own some sort of business or have a good career.

When I was a kid I felt like nobody understood me or what I was going through. I was embarrassed and felt really worthless. Having MS is hard, but having MS as a kid is really hard, because you don't know what to do – MS didn't come with a guide book on how to handle it. Sometimes I didn't even want to go out with my friends because I thought I was holding them back. No kid should get MS. It is so hard to go to school and be surrounded by healthy kids when you're sick. Thankfully, every summer I go to MS Summer Camp, organised by the MS Society of Canada (www.mssociety.ca/camp) where I meet other kids with MS – they have become another family to me.

"Take a deep breath; you have MS, MS doesn't have you." This is one thing I tell myself when I start getting negative. I have spent many days and nights feeling depressed but it finally hit me. Being negative and sad doesn't help my situation so there's no point of stressing. Now how does someone not stress over having this disease? I'll tell you what helped me. F.U.MS (f*** you multiple sclerosis) is my motto; I live by this. I keep close with my friends and try to laugh as much as possible, but when negative thoughts do come, I repeat F.U.MS over and over.

I also try to take my medications and I've started going to the gym and eating in a healthy way. I would tell somebody that just got diagnosed to hold on; this thing is hard, but you're harder. You never asked for MS so don't ever be ashamed of it or let it kill your confidence. Instead embrace your situation so no one could ever use it against you. Finally I would tell kids with MS to come to MS Summer Camp and join the MS family, it helped me a lot.

How MS organisations support young people with MS around the world

MS Society of Canada

Someonelikeme.ca and Commemoi.ca are unique websites which feature blogs, information, forums and inspirational stories of young people affected by MS. Many young people express that they feel very alone after receiving a diagnosis for themselves or a family member. Someonelikeme and Commemoi help fill that need by creating a community of people who understand and want to share their stories and encouragement with each other. We invite young people aged 15-35 from across the world to visit, share, join and find support and inspiration.

The MS Summer Camp offers the opportunity for youth (ages 8-21) with MS to enjoy a week of fun and adventure (pictured below) while providing respite from the stresses associated with MS. Campers are also introduced to older peers who have followed their dreams despite their MS diagnosis. One camper said "Camp makes me feel comfortable and not alone with this disease. The one week of MS camp makes a huge difference in my life!" (*Contact: kidsandteenscamp@mssociety.ca or www.mssociety.ca/camp*)

German MS Society

There are many programmes for young people around the regions in Germany including discussion groups, workshops, information events, camps (contact: www.u30-camp.de), websites (www.kinder-und-ms.de) and a German-speaking international community on facebook of about 450 members: (https://www.facebook.com/groups/wir.haben.die.kraft).

(Contact: DMSG, Bundesverband e.V.; Gabriele Seestaedt, email: dmsg@dmsg.de)

Swiss MS Society

Annual MS Youth Congress

In 2012, the Swiss Multiple Sclerosis Society launched the first annual MS Youth Congress in Zurich, Switzerland. This event is for young people with MS and their caregivers. It offers a platform for discussion and workshops, as well as lectures by experts. Young people can get together and exchange views and opinions, and are also given the opportunity to make suggestions to the MS Society for future programmes and services. *(Contact: Kathryn Schneider, kschneider@multiplesklerose.ch)*

Norwegian MS Society

For families who have a child with MS: This 3-4 day annual meeting aims to give children and young people with MS and their families the opportunity to meet and network with other families. Through knowledge, games and social activities we give families tools to cope with MS in everyday life. *(Contact: Gurli Vagner, gurli@ms.no)*

Local meetings for young people: Young people from branches are invited three times a year to meet other young people and exchange experiences, so they can advise other young people in their local branch. (*Contact: Bjørn-Anders Foss Iversen, bafi@ms.no*)

Italian MS Society

National Conference of Young People with MS

Since 2009, this two-day event brings together 250 young people to discuss the research, therapies, MS management and issues related to young people with MS. A group of young people help plan the conference, which offers question and answer sessions with top MS researchers and clinicians, as well as discussion groups on topics such as starting a family, employment and disclosure, and rights and empowerment. For many young people, attending the conference is their first opportunity to meet other people with MS and to connect with the MS Society. (*Contact: Silvia.Traversa@aism.it*)

MS Ireland is working to support young people with MS and provide opportunities for them to engage with each other. For example, information evenings for people newly diagnosed with MS which look at social/government supports, counselling services and the role of regional community workers; an informal group run by young people in Dublin (www.meetup.com/Dublin-Multiple-Sclerosis-Group); a social group for young people in Cork; and a physiotherapy, yoga and exercise programme. (*Contact: www.ms-society.ie or info@ms-society.ie*)

Spanish MS Association:

Association of Salamaca: "Fresh Air"

This programme aims to meet the needs of people 18 to 40 years. It offers a chance to know other young people who have MS, learn about MS and how to adapt to it, and share their concerns with each other or with professionals. *(Contact: Estafania M. Caselles, info@adem.org)*

Association from Jaén, Virgen del Carmen: Get-together for young people with MS

This peer support group for young people offers them an opportunity to meet others, share experiences and relax together. *(Contact: Marcos David Cabrera Barranco, Youth Representative on Executive Board of AJDEM, ajdem.joven@gmail.com)*

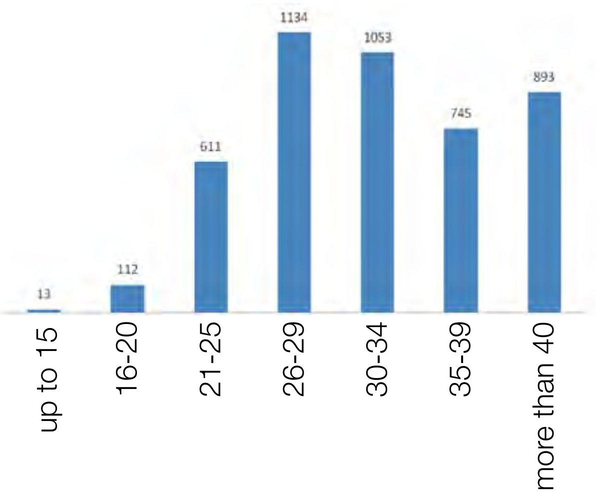
Shift.ms is a global community of young, friendly and positive MSers. Members can share, support and interact with each other throughout the site. Shift.ms believes that MS doesn't mean giving up on your ambitions, just rethinking how to achieve them. Find out more and join at www.shift.ms

Results of the young people with MS survey

More than 4,600 people from around the globe took part in the *MS in focus* online survey about living with MS as a young person.

The respondents were from more than 100 countries and three quarters were female. The age range is shown in Graph 1. The majority of respondents were diagnosed between the ages of 21 and 30 and 67% had relapsing-remitting MS (3% had progressive relapsing, 4% had primary progressive, 7% had secondary progressive and 19% said ‘other’ or ‘unsure’.)

Graph 1: Age of respondents

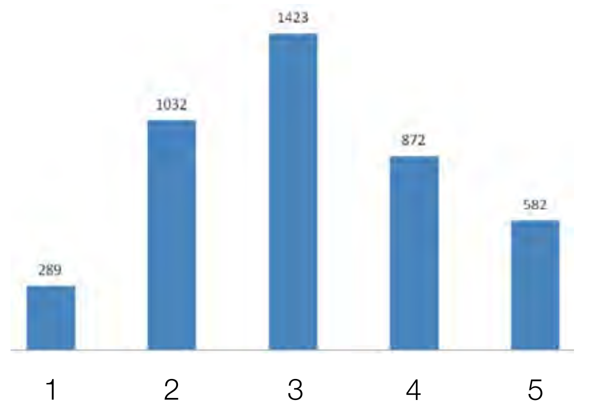


Section two of the survey was formed of statements about living with MS and respondents were asked to select the answer that most related to them. The majority of responses were relatively positive, for example for the statement “I avoid seeing my friends and family because of my MS”, the majority (53%) said ‘never’ (37% said ‘sometimes’, 8% said ‘often’ and 1% said ‘all the time’). 84% said that the statement “All of my friends know that I have MS” was true or somewhat true. For the majority of respondents (55%), “MS stops me from doing the things I want to do” “sometimes”. At the same time, there is also an acknowledgement of the burden of the disease, for example 60% said they feel angry ‘sometimes’ about their MS.

> *“I do everything for myself, but I get emotional help from my grandma who also has MS.”*

Section three about impacts and concerns showed that the level of concern seems more evenly distributed when it comes to the impact of MS on family and friends, leisure activities and self image, but is shifted towards “very concerned” for current or future partner, school/university/work, life in the future and mental health. These represent targets for educational interventions and for services. Overall, the majority of respondents said that MS had a rating of 3 on their day-to-day life, where 1 is “no impact” and 5 is “huge impact” (see Graph 2).

Graph 2: Impact of MS on day-to-day life

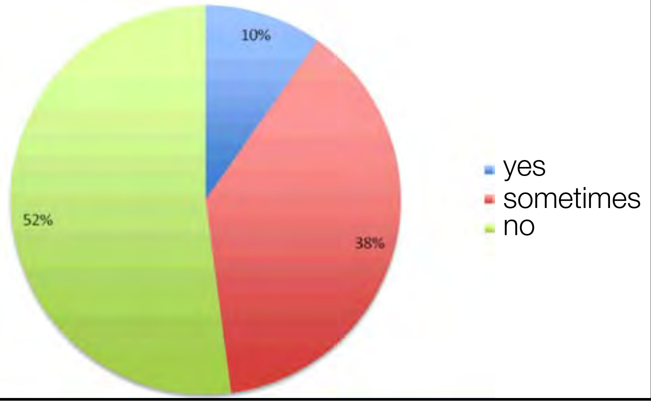


More than half of respondents said they didn't need support day-to-day (see Graph 3). For those that did, family was the primary source of this support, with friends also helping at work or school and with emotional support.

This finding underscores the importance of considering the consequences of MS on the family, and what will happen in the future if family can no longer provide this support.

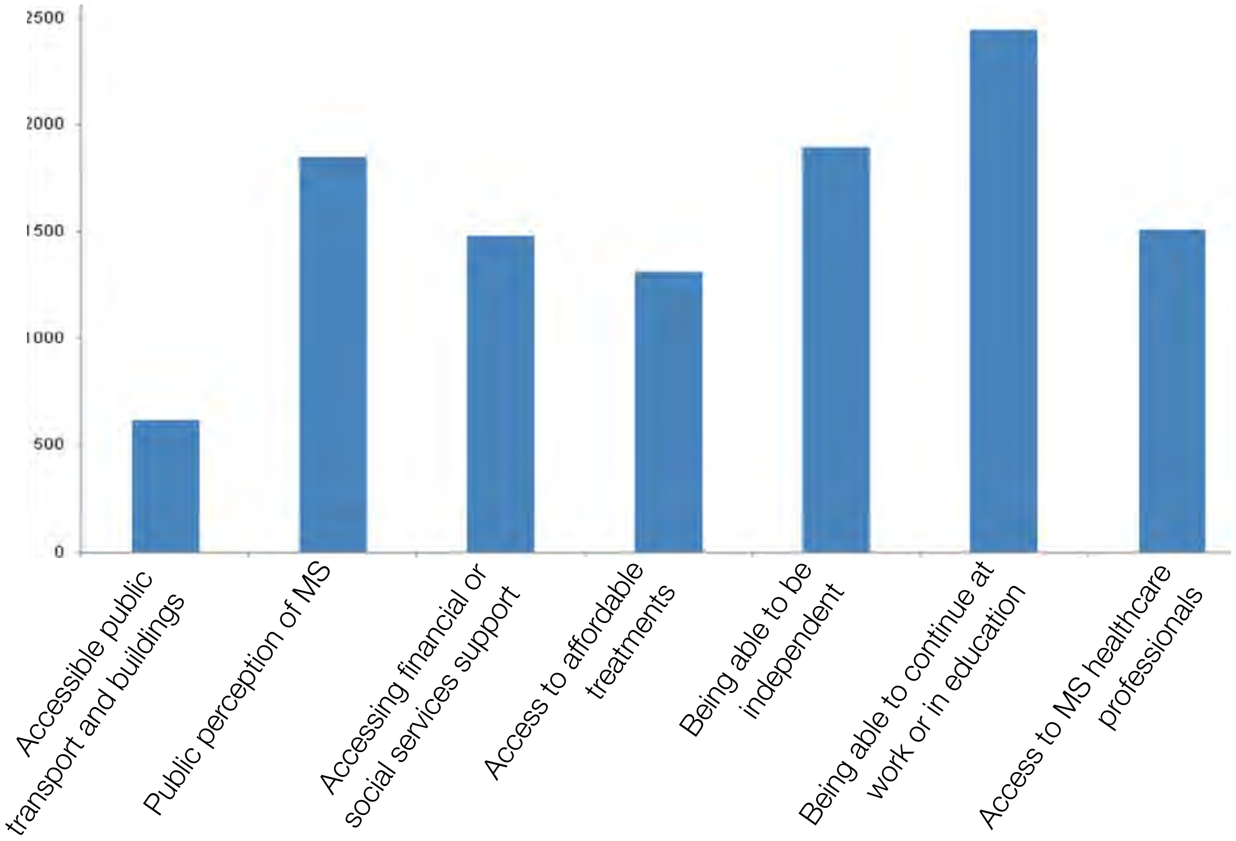
Respondents were interested in various information topics, in particular treatments (21%) and keeping healthy (diet, exercise etc) (19%), and go to multiple sources for information, with the most common being websites (25%) and doctor/nurse (22%).

Graph 3: Do you need support to undertake your day-to-day life?



When asked about the three most important issues for young people in their country, the results showed that these were: being able to continue at work or in education, being able to be independent and the public perception of MS (see Graph 4).

Graph 4: What are the three most important issues for young people with MS in your country?



MSIF Member Society contact details

Argentina: Esclerosis Múltiple Argentina
info@ema.org.ar; www.ema.org.ar

Australia: MS Australia
info@mssociety.com.au www.msaustralia.org.au

Austria: Multiple Sklerose Gesellschaft Österreich
msgoe@gmx.net www.msgoe.at

Belgium: Ligue Nationale Belge de la Sclérose en Plaques/Nationale Belgische Multiple Sclerose Liga
ms.sep@ms-sep.be www.ms-sep.be

Brazil: Associação Brasileira de Esclerose Múltipla
abem@abem.org.br www.abem.org.br

Canada: MS Society of Canada /Société canadienne de la sclérose en plaques
info@mssociety.ca www.mssociety.ca
www.scleroseenplaques.ca

Cyprus: Cyprus Multiple Sclerosis Association
multipscy@cytanet.com.cy www.mscyprus.org

Czech Republic: Unie Roska ceská MS spolecnost
roska@roska.eu www.roska.eu

Denmark: Scleroseforeningen
info@scleroseforeningen.dk www.scleroseforeningen.dk

Estonia: Eesti Sclerosis Multiplex'i Ühingute Liit
post@smk.ee www.smk.ee

Finland: Suomen MS-liitto ry
tiedotus@ms-liitto.fi www.ms-liitto.fi

France: Ligue Française contre la Sclérose En Plaques
info@lfsep.asso.fr www.lfsep.com

Germany: Deutsche Multiple Sklerose Gesellschaft Bundesverband e.V.
dmsg@dmsg.de www.dmsg.de

Greece: Greek Multiple Sclerosis Society
info@gmss.gr www.gmss.gr

Hungary: Magyar SM Társaság
smkozpont@albatct.hu www.smtarsasag.hu

Iceland: MS-félag Íslands
msfelag@msfelag.is www.msfelag.is

India: Multiple Sclerosis Society of India
mssiheadoffice@gmail.com www.mssocietyindia.org

Iran: Iranian MS Society
info@iranms.org www.iranms.ir

Ireland: MS Ireland
info@ms-society.ie www.ms-society.ie

Israel: Israel MS Society
agudaims@netvision.net.il www.mssociety.org.il

Italy: Associazione Italiana Sclerosi Multipla
aism@aism.it www.aism.it

Japan: Japan Multiple Sclerosis Society
jmss@sanyeicorp.co.jp www.jmss-s.jp

MSIF Member Society contact details (continued)

Latvia: Latvijas Multiplas Sklerozes Asociacija
lmsa@lmsa.lv www.lmsa.lv

Luxembourg: Ligue Luxembourgeoise de
la Sclérose en Plaques
info@msweb.lu www.msweb.lu

Malta: Multiple Sclerosis Society of Malta
info@msmalta.org.mt www.msmalta.org.mt

Mexico: Esclerosis Múltiple México
emmex-org@hotmail.com http://emmex-ac.blogspot.com

Netherlands: Stichting MS Research
info@msresearch.nl www.msresearch.nl

New Zealand: MS Society of New Zealand Inc
info@msnz.org.nz www.msnz.org.nz

Norway: Multipel Sklerose Forbundet I Norge
epost@ms.no www.ms.no

Poland: Polskie Towarzystwo Stwardnienia Rozsianego
biuro@ptsr.org.pl www.ptsr.org.pl

Portugal: Sociedade Portuguesa de Esclerose Múltipla
spem@spem.org www.spem.org

Romania: Societatea de Scleroza Multipla din România
office@smromania.ro www.smromania.ro

Russia: The All-Russian MS Society
pzlobin@yahoo.com www.ms2002.ru or http://ms2002.ru/

Slovakia: Slovenský Zväz Sclerosis Multiplex
szsm@szm.sk www.szsm.szm.sk

Slovenia: Združenje Multiple Skleroze Slovenije
info@zdruzenje-ms.si www.zdruzenje-ms.si

Spain
Asociación Española de Esclerosis Múltiple
aedem@aedem.org www.aedem.org
and
Esclerosis Múltiple España
info@esclerosismultiple.com www.esclerosismultiple.com

South Korea: Korean Multiple Sclerosis Society
kmss2001@gmail.com www.kmss.or.kr

Sweden: Neurologiskt Handikappades Riksförbund
nhr@nhr.se www.nhr.se

Switzerland: Schweizerische Multiple Sklerose
Gesellschaft
info@multiplesklerose.ch www.multiplesklerose.ch

Tunisia: Association Tunisienne des Malades de la
Sclérose en Plaques
ATSEP@topnet.tn contact@atseptunisie.com
www.atseptunisie.com

Turkey: Türkiye Multipl Skleroz Dernegi
bilgi@turkiyemsdernegi.org www.turkiyemsdernegi.org

UK: MS Society of Great Britain and Northern Ireland
info@mssociety.org.uk www.mssociety.org.uk

Uruguay: Esclerosis Múltiple Uruguay
emur@adinet.com.uy www.emur.org.uy

USA: National MS Society
www.nmss.org

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multiple sclerosis
international federation

Skyline House
200 Union Street
London
SE1 0LX
UK

Tel: +44 (0) 20 7620 1911
Fax: +44 (0) 20 7620 1922
www.msif.org
info@msif.org

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With many thanks

MSIF would like to thank Merck Serono for their generous unrestricted grant, which makes the production of MS *in focus* possible.