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Introduction

The Listening to People with MS Initiative launched in 2012 with the goal to increase the MS Society's understanding of current quality of life needs, priorities, gaps and barriers experienced by Canadians affected by MS. The initiative is comprised of four research components: 1) an on-line poll; 2) an on-line survey; 3) an environmental scan; and 4) focus groups. All four components will gather information about MS-related quality of life issues. This report provides an overview of the results from the focus group component of the initiative.

Focus groups are conducted to probe for qualitative information in a way that typical surveys are unable to. Although a valuable research tool, surveys generally ask closed-ended questions that may limit the feedback that can be gained from a participant. Focus groups provide the opportunity to garner this more in-depth feedback through open-ended questions. They also allow for group interaction between members of the group which may encourage participants to make connections to various concepts through the discussions that may not occur otherwise. This can provide a more comprehensive understanding of what is being studied (Richard Kruger and Mary Anne Casey, 2009. *Focus Groups: A Practical Guide for Applied Research*. Fourth Edition. SAGE Publications). Accordingly, the Listening Initiative focus groups were conducted to expand on the findings of the on-line poll and survey.

Methodology

Focus groups were conducted in every MS Society Division across Canada. The bulk of the groups were with people diagnosed with MS although there were also two specialized groups conducted: one with caregivers and one with youth with MS. Convenience sampling methods were used to recruit participants. Specifically, participants were recruited by local staff at both the chapter and division offices using a variety of strategies including information flyers at local chapter offices and MS Clinics, information on Division web-sites and newsletters, word of mouth through MS Society volunteers, direct calls to potential participants, and invitations at support groups. Recruitment for every group took into consideration a mix of gender, type of MS, years with MS, age, cultural background, place of residence (i.e. rural and urban locations, supportive care and long-term care residences) and progression of the disease to ensure that a wide demographic profile was represented at each group. Staff recruited 10-12 participants per group. All groups were 2 hours in length with refreshments and food provided to the participants. Participants were not paid for their participation although travel expenses were provided for some.

Two scripts were developed for the facilitator to guide the group discussions: one for the group with people diagnosed with MS and the other for the group with caregivers. The scripts explained the purpose of the group, reviewed the focus group rules, and reinforced the confidentiality of all the discussions. It provided a series of open-ended questions with additional probes and prompts to encourage discussion and explore the issues in more depth. A copy of the scripts can be found in Appendix A.

The groups followed a semi-structured format in that they opened with introductions and information sharing about MS. A transition question was then asked to introduce the topic of quality of life to help participants discuss the issues on a broader scope. Then specific questions and probes were asked but not necessarily in the same order at each group. This semi-structured format was used to ensure that the key topics were discussed at every group so that information can later be compared from one group to another while also allowing for free flowing discussion. One facilitator conducted the majority of the

groups although the French group and the youth group were conducted by different facilitators using the same script. All sessions were tape recorded and participants signed waivers to ensure privacy and confidentiality of all discussions.

The findings from the focus groups were analyzed using a thematic analysis approach that was conducted by the primary facilitator. The first step in this analysis involved playing back the recordings of each group while concurrently reviewing and enhancing the summary notes. Then, for every group, the key themes regarding each research question were summarized. These themes were then compared and collated across all groups. Common themes emerged from every group and have been summarized in this report.

Participants

A total of eight focus groups were held in the following locations: Halifax (Atlantic Division), Montreal (Quebec Division), Toronto (Ontario Division & National youth group), Winnipeg (Manitoba Division), Regina (Saskatchewan Division), Calgary (Alberta Division) and Vancouver (BC Division). Six of the groups were conducted with people diagnosed with MS. One group was conducted with caregivers of a person with MS and one was conducted with younger people with MS (ages 18-34 years). Every focus group had 6 - 12 participants and included a broad demographic composition. Each group included members from both genders, both relapsing-remitting and progressive forms of MS, a variety of ages, varying levels of disease progression, both rural and urban residents and a variety of cultural backgrounds. Two groups included a member who resided in either supportive or long-term care facilities. To ensure a broader geographic representation, several of the groups included participants via teleconference.

Results

Defining Quality of Life

After introductions were made, the focus groups commenced with a group discussion and brainstorming exercise about what quality of life means to people. The participants were asked to describe what a good quality of life means to them. The themes from these discussions were identical across the country and reflect the MSIF quality of life principles. People talked about the importance of maintaining their independence and autonomy. They spoke about not wanting to be a burden to family and friends. Maintaining the freedom to make lifestyle choices and to participate in activities of their choice was also important. Continued participation in community life, be it volunteer work, employment or social activities was also mentioned. Feeling 'normal' or not being singled out was noted by all participants but was particularly important for younger people with MS. The idea of the stigma of looking and feeling different was a difficult issue for the participants and had an impact on their quality of life. Finally, the issue of having adequate finances to allow people to live in their own homes, eat healthy and nutritious food, engage in social activities and to generally participate in life activities was an extremely important component of maintaining a positive quality of life.

I want to be able to do what I want, when I want, how I want.

Quality of life means having the freedom to choose from many possibilities; to be able to apply my skills and talents and to engage in my community in a meaningful way.

It is important for me to be able to help myself and not have to rely on others. I want to keep my independence. This is so important for my quality of life.

Like everyone, I want to live a 'normal' life with a balance of work, love and play. Having MS doesn't change this desire.

Participants also spoke about how MS impacts their quality of life. Participants talked about the challenges relating to the uncertainty of the disease and the fact that the symptoms are challenging both physically, mentally and emotionally. The general conclusion was that MS takes away many of the basic requirements for a good quality of life: finances, independence, certainty and stability, and freedom. Accordingly, the participants talked about the importance of accepting this reality, setting realistic expectations and redefining goals as the disease progresses. People who had more progressive forms of MS and those who have had the disease for longer noted that, over time, things they could once do are no longer physically possible for them; thus requiring them to change their expectations and accept the changes. This concept of acceptance was discussed at length by the participants. Most felt very strongly that this acceptance of change and redefining of expectations is critical to emotional wellness and maintaining a good quality of life. They indicated that keeping a positive attitude is critical to finding contentment and acceptance of life with MS and all that it brings.

This disease is different for every person. Your attitude is everything and strength and power will get you through but you also need to accept your reality and future needs because you are never in the same place twice.

Before I had MS I was doing a lot of different things and lived a different life. I don't know what I would be doing now if I didn't have MS. But I can't look back because this is my life now. This is the hand I have been dealt and I need to accept it, deal with it and live my life.

I try to find the positive things. Being in a wheelchair means I don't have to drive on icy roads anymore or walk on icy sidewalks. I get to drive my wheelchair instead!

Caregivers who participated in the focus groups also defined quality of life in the same way as those diagnosed with MS. The importance of independence, freedom to choose life activities, involvement in community, and living a 'normal' life were all noted by caregivers. Additionally, the caregivers discussed the importance of remembering to separate their caregiving responsibilities from their relationships with the person with MS. They spoke about the need for setting boundaries and finding time for themselves to keep a good quality of life. The caregivers also talked about the physical changes related to MS and the accompanying challenges of finding transportation, maintaining a sexual relationship with their partner, accessing activities and programs that allow for independence and how all of these aspects influence the quality of life with MS.

Programs to Support Quality of Life

The participants were asked to describe the various types of programs they are currently participating in that help to support and improve their quality of life. The groups noted that a wide variety of programs and services that address the various aspects of quality of life are important. Addressing the physical, mental, social and emotional aspects of wellness is very important to the participants. Again, this reflects the MSIF Quality of Life principles. Interestingly, there was also a strong theme across all groups that participation in exercise, above any other type of activity, is extremely important in slowing the progression of MS, reducing pain associated with the disease and maintaining a good physical and mental health.

The fun factor is important. It's really important to continue doing things and if you are getting enjoyment from it, that is half the battle. You need to think about the physical, mental and social aspects of your life and keep active in all those parts of life.

Fitness is so important for physical energy. Working out helped me. It changed me overnight. I started doing cardio and felt much better cognitively and physically.

Exercise is the most important thing to help with MS. My symptoms were much worse before I started exercising. Now, I know my MS is progressing more slowly because I exercise.

In terms of types of programs, the focus group participants indicated that they participate in a wide variety of activities including exercise programs (e.g. yoga, strength training, swimming, etc.), social activities, support groups, volunteer activities, and education programs. These programs and activities were offered by numerous organizations including, but not limited to, the MS Society. The participants feel that it is very important to be involved in their communities through church, recreation centres, local MS Society offices, employment, schools and education. However, they also noted that participation in programs is limited by two things that have a significant impact on their ability to stay involved or participate: finances and accessibility. In terms of finances, the message from the participants was consistent across the country - you must have enough money to pay for programs. They indicated that many programs are expensive and, when you are on a limited income, this prohibits participation. They noted that when you cannot participate you become isolated, depressed and anxious. Ultimately, having access to finances or financially accessible programs has a significant impact on a person's quality of life.

Accessibility also has a significant impact on quality of life for all people living with MS (not just those with limited mobility). Participants talked about the challenges of finding programs and facilities that are accessible for those in wheelchairs, scooters or using other mobility aids. Finding accessible transportation to get to programs is also a challenge for many. There is a feeling that there are many places that are not physically accessible. Additionally, other accessibility issues came up around fatigue, heat management, bladder/bowel control problems and cognitive limitations. Participants spoke about the challenges of registering for a program and then missing many sessions because they were too tired to attend. The issues of bladder and bowel control were also discussed in the context of being able to participate when you cannot control these bodily functions and the accompanying embarrassment or anxiety of coping with these issues in public places. Participants also indicated that many facilities are too hot for people with MS, particularly for exercising. Finally, the cognitive symptoms of MS can also create a barrier to participation in programs. Participants who are experiencing cognitive limitations as a result of their MS spoke about having difficulty accessing programs and services because of a lack of ability to find them or obtain information about them. They also talked about feeling anxious about attending programs because of their cognitive limitations, not understanding others and feeling self-conscious or stupid because of these limitations.

I have a limited source of income. It becomes unreachable to participate in exercise programs in the really good fitness centres.

I don't live in a major city centre. I can't afford to have a trainer to show me how to adapt exercises to meet my needs. I don't drive and there is no para-transit in my area. So I can't participate in exercise programs.

My main MS symptoms have always been neuropathic pain and cognitive challenges. I often find it hard to follow conversations or understand what is being said to me so I sometimes just

pretend to follow what they are talking about. But I am not processing the information that I need to. It makes it really hard to participate in anything when my brain isn't working at the same speed as everyone else around me.

Gaps in Programs and Services

The group discussions also focused on where there are significant gaps in programming and services that improve quality of life. While there were some community-specific issues raised, broader-based gaps that apply across the country were the primary concerns. The lack of specially-trained physiotherapists with an intimate knowledge of and experience working with people with MS was noted across the country. Many participants had the need for physiotherapy but they have difficulty finding ones who understand MS and have in-depth, practical knowledge of the disease. Participants also commented that there are very few outpatient rehabilitation services available and the ability to pay for the few services that are available is an issue. There is the feeling that, in many provinces, the move to centralize health care services has resulted in significant gaps in access to rehabilitation and specialized services in smaller communities. Along this line, the participants also talked about the long waiting lists in every province to see an occupational therapist for an assessment which is a necessary requirement to receive most types of government funding for equipment, programs and health services. This was a point of frustration for most of the participants.

With the physical changes I was experiencing, I was looking for a physiotherapist. I couldn't get pointed to one, even when I called the MS Society.

I tried physiotherapy for a year and a half to help me to walk better. But the therapist told me I couldn't improve. She didn't know enough and would not listen to me. So I stopped going and started working out at a gym and saw improvement in my walking.

The lack of home care services was also commonly noted and much discussed across all the groups. The participants either have a current need or see a future need for personal care at home so that they may live at home independently - an important aspect for their quality of life. However, the majority of those who have tried to access home care were frustrated and disappointed with the experience. They spoke about the long wait times for OT assessments that provide approvals to receive home care services. Then, they had to wait again for weeks (sometimes months) to actually receive the services that had been approved. Additionally, there was great frustration and, in some cases, despair, expressed around the lack of personal support workers available to help with basic needs of daily living. People need help with food preparation and light housework but it appears that these types of services are often not available. Additionally, there were many concerns expressed about the quality and reliability of home care services. While there were many stories of wonderful home care workers, there were equally as many negative experiences cited. It is common for staff to be very late for appointments, leaving people in bed for hours. Participants also talked about poorly trained staff that were unable to provide necessary services. Seeing a different person every few months was also a common issue for many, causing disruption to the lives of people already challenged due to their progressively worsening symptoms. Further compounding the issue is the variability noted between regions within a province or even a city in terms of the types of services offered. Some participants indicated that they had access to assistance with light housekeeping while others, from the same province, said that those services were not offered in their region. The sense of unfairness and aggravation this caused for many people was evident from the discussions.

The available services for home care are different from one local clinic to another. It isn't fair that my friend living in one part of the city gets help with her housework when I am left to struggle on my own, just because of where I live.

It is so hard to deal with home care, it almost isn't worth it! There are always staff shortages so I never know who is coming, what time they are coming and if they will be trained to help my wife.

There are many days when she doesn't get out of bed until the afternoon because the home care nurse didn't show up at 10 in the morning when she was supposed to. Or the one that shows up hasn't been trained to bathe her so she refuses to do it.

I can't shower on my own anymore and I have to wait for the home care worker to help me. Well, there are times when I don't get a shower for days because the worker was off sick and there was no one to replace her.

The lack of age-appropriate long-term care facilities was also a gap noted by many focus group participants. Although there were only two participants who actually reside in supportive care/long-term care facilities, many participants knew of someone or had heard about a younger person with MS residing in a long-term care facility. The fear of this happening to them was strong and is a major worry for the participants. There is a belief among the group participants that there needs to be greater lobbying of the government to create long-term facilities that are suitable for younger people with MS.

There is no facility for younger adults in the entire province where you could be looked after appropriately.

I know someone with MS whose biggest issue in living in a long-term care facility is his roommates kept dying on him.

The participants also relayed their stories about their experiences with employers. There was a wide range in the experiences with some describing very negative encounters and others recounting very positive and supportive ones. However, the general conclusion from the employment discussions was that most employers are not as supportive as desired and most people will end up leaving their job and having to collect some type of income replacement (e.g. CPP-D, long-term disability, etc.). The fact that many people work in contract positions now also factored in, in that employers are less likely to accommodate a contract employee. It is easier for them to find someone else. The participants indicated that more effective and available employment counselling is a critical gap in the current system. They suggested that counselling is required to help people with MS find employment that will work with their disease symptoms. They also suggested that they need counselors to work with their employer to find alternative work arrangements that are suitable for everyone. It was also noted that support and advice are required for people who are recently diagnosed with MS as to how to talk to their employer. Most of the participants struggled with how and when to disclose their diagnosis with their employer and many had received conflicting advice from their doctors, friends and family. They did not know where to go for support on this and who to contact for accurate and helpful advice. For younger people diagnosed with MS the employment issues and the need for counselling was even more pronounced as many are still in school and will be seeking employment, feeling unsure about what type of work to look for and how to talk to potential employers without fear of discrimination because of their MS diagnosis.

A lot of companies want to hire disabled people. But how do you find them? We need a job developer who understands MS to help people find jobs.

I had been with my employer for 5 years when I was diagnosed. I am now on LTD because of an injury and my job has been eliminated. But I am still young and want to work so I'm looking for a job. As someone with a serious illness I need to feel able to disclose appropriately and a job counselor would be very helpful. I don't know what to do or where to go right now.

My employer was understanding but a little bit intimidated – they didn't know what to do. I went in prepared to ask for what I needed. This is where the MS Society can help us.

Respite care was the final gap noted by the focus group participants. Interestingly, the lack of appropriate and available respite care was brought up not only by the caregiver participants but also by those diagnosed with MS. Most of the groups with those diagnosed with MS spent time discussing the needs of their friends and family members who provide them with informal care. Stories of the sacrifices made by husbands, wives and children were shared by many. They all agree that their caregivers need to find a balance between providing care, advocacy and support, and meeting their own needs and taking care of themselves. The fear and guilt of being a burden on their loved ones was also point of discussion. Those diagnosed with MS also want their loved ones to do things on their own and not feel guilty about that. Caregivers spent a lot of time lamenting the lack of respite care. They noted that there are not enough beds in care facilities so it is difficult to find space for their loved one. They also indicated that not all facilities have the same equipment or appropriate facilities to meet the needs of a person with MS. Several negative experiences were shared that made the caregivers feel reluctant to place their loved one in respite again. Both caregivers and people diagnosed with MS also talked about the need for day-to-day respite through day programs, home care or other types of services that would allow caregivers at least a short break on a more regular basis. The consensus is that there are very few respite care options, either for overnight stays or daily breaks, available anywhere in Canada.

When you have MS, the whole family has MS.

I left my wife in one place where the staff avoided using bedpans. So she was forced to use diapers. How can I leave her in a place like that? The guilt is too much.

Barriers to Quality of Life

The issue of accessing financial support was a major point of discussion at all of the focus groups. Everyone felt that having enough money to do things, buy medications and medical supplies, participate in programs, get extra therapies, etc. is critical to having a good quality of life with MS. They talked about how MS is an expensive disease which is compounded by the fact that many people are unable to work so cannot earn money. Many people shared horror stories of the issues they faced in collecting their STD and LTD entitlements. They spoke about being spied on by the insurance companies, feeling like a criminal for asking what they are entitled too, completing the same form every 3 months, harassing their doctors to get forms completed and then even having to fight legal battles to overturn rejected applications. Other participants talked about the process of applying for CPP-D and the challenges of completing the various forms. The consensus among all the participants is that income replacement programs do not provide you with enough money to live a good life. They feel the lack of adequate financial resources is a significant barrier to achieving a good quality of life. At every group there were several participants who expressed sincere gratitude to the MS Society for the financial support they provide. Although all agreed these supports are minimal, they made the point that even a small amount can make a huge difference in someone's quality of life. It can mean they are able to eat a

better meal because the support they received from the MS Society paid for something that they would have otherwise had to use their grocery money for.

There was also discussion about the lack of tax credits available to people with disabilities and people with MS. The difficulty of navigating the tax system and understanding the various options available was a huge issue for people. Many were surprised to learn from other members of the focus groups about tax credits they could claim, demonstrating the lack of knowledge of most people regarding the Canadian tax system. Everyone agreed that income, finances and accessing related financial support services is a large barrier to the quality of life of those living with MS.

I worry about the financial burden of the future. I can buy food tomorrow but you don't know how many years you will be able-bodied. How do I save up enough to live a full life? What will my quality of life be like in a few years when I can't work? It scares me.

I had to go months without income. I went from making \$30,000/year and owning a house to no income, dodging creditors. I went to churches for charity, food banks and whatever I needed to clothe and feed my son. There was a gap in information everywhere along the way.

You can't live off of the CPP-D amount. And you can't really work because they take the little they are giving you away if they find out you are earning money somewhere else. So you get stuck in a bad cycle that you can't get out of.

Accessible transportation was another barrier noted by the focus group participants. For those with mobility issues, finding transportation that is accessible, convenient and usable can be a challenge. Some municipalities seem to have better systems than others but, even the 'good' ones, appear to have issues. Participants talked about having to book rides with handitransit/paratransit systems days or weeks in advance. They talked about the unreliability of these services around timing – they are notoriously late so clients have to build in hours of buffer when they are planning to use the service. While many municipalities are providing a greater number of wheelchair accessible buses and subways, there are still logistical issues in accessing these vehicles. For instance, several participants talked about the ice build-up on ramps causing problems. Or subways that don't stop long enough to maneuver a wheelchair into the car. They also mentioned that not all buses and subway cars are accessible so people often have to wait for long periods of time for an accessible vehicle to arrive. People with cognitive symptoms discussed being treated rudely by transit staff. Those with walkers and canes talked about the difficulties getting onto public buses and subways. People spoke about the challenges of finding taxis that will accommodate a wheelchair. Ultimately, all of these issues create anxiety and frustration which result in people not being able to participate in their community thus impacting their quality of life in a negative way. There was also a lot of discussion about the lack of cross-municipality services that create significant challenges for people with MS. Transit systems in different regions are not structured the same and often require different application processes. Many participants have to travel between municipalities, particularly to access MS Clinics that may not be in their local community. The difficulty of moving between regions creates a significant barrier for these individuals.

Even though I am not in a wheelchair I find the public transportation system very challenging. You need arm and leg strength to walk down to the subway and to get into the buses. I am often too weak and tired to do this.

The bus driver tells me to move out of the disabled spot because I look young and my disease is invisible. Now I bring my cane so people can identify my disability.

You have to plan very far ahead to book the handitransit. And you have to call at inconvenient times and try several times before you can get through. It often isn't worth the bother. But then I don't get out. So what do you do?

Accessible buildings and spaces were also discussed at the groups. While everyone agreed that Canada does fairly well in creating accessible spaces, there are still significant issues. Most of the participants dealing with restricted mobility told stories of challenges they regularly face in conducting their daily activities that most people take for granted. Accessible washrooms seem to be a significant concern for everyone. Although most public buildings have wheelchair accessible stalls there are often other logistical details that are not addressed. For instance, the height of the sink is too high or low, the placement of the soap and towel dispensers is too high, only one grab bar in stalls, doors that are not wide enough, and doors that are too heavy were all noted by participants. Additionally, participants mentioned that many restaurants have bathrooms in the basement, making it a challenge even for those not requiring a wheelchair. The use of interlocking brick and sidewalks that are uneven were also discussed as significant barriers. Grocery stores that place their shopping carts too far from the disabled parking or the entrance are daily challenges. All of these seemingly small issues have a huge impact on a person's daily life, their ability to get around and stay active in their community; ultimately, having a negative impact on their quality of life.

My local municipal building has the worst 'accessible' washroom. The large stall is fine but the sink location is set up so that I end up practically sitting in the urinal in my scooter while trying to wash my hands. These architects do not really know what accessible means. It is about more than the size of the stall.

Access to information, at the right time, in the right place was also a big barrier for the focus group participants. This theme was brought up time and again at every group. There is a feeling among the participants that, although there is a lot of information out there, finding it can be challenging. They feel you have to seek out what you need, that the information is not all in one easily accessible place. The participants talked a lot about having to advocate for yourself, to use word of mouth to learn about programs and services and the amount of time they have to spend finding the specific information they need. Many participants expressed that they constantly have to seek out information. There are so many questions about this disease and so much is still not known so they often don't know where to go to learn what they need. The types of information needed ranged from programs and services, disease and symptoms, medication options, income support, tax credits, professionals to help people with MS, how to access clinical trials and travelling with MS. Several expressed a desire for information directed towards teens whose parents have been diagnosed with MS. Many participants mentioned that they had received an excellent package from the MS Society when they were first diagnosed while others were not happy with the information and support they received. Many participants find the MS Society web-site a good source but not everyone feels this way. Overall there was a general dissatisfaction with the information available, particularly about services and programs for people with MS.

Sometimes I don't know what my needs are. I don't know what questions to ask to find the things that would benefit me. If I knew all the other things, maybe I could pick things that would help. In the meantime, I sit and wait and hopefully come out on top.

You have to be proactive. It's about asking questions and the services should perhaps be advertised more.

I want quality of life information not just information on my medications. Like what you could do if you want to travel, exercise, do something with your kids that is appropriate with the progression of your disease.

There is respite care available through the March of Dimes. I wasn't even aware of this. Why can't I call the MS Society and be told about these types of services? It is hard to ask about services if you don't even know they exist.

People don't know what they can participate in. Sometimes it is who you know. Networking is key.

Navigating the Health Care System

There was a lot of discussion among the participants about the health care system and how it does not meet the needs of people affected by MS. Everyone shared stories about the lack of integrated, continuous and quality care in the system. The problems range from diagnosis to treatment to the provision of home care. The issues mentioned by the participants include the challenges in getting diagnosed, the long wait times for tests and specialist appointments. Many people talked about the lack of empathy on the part of their doctor when they were told the diagnosis was MS. Additionally, there is a lot of frustration among the participants about decision-making regarding treatment options. Similar stories were shared about being provided with a booklet by the neurologist who told them to read it and decide which drug they wanted to try. They feel that there is not enough support during the treatment decision-making process. They feel they are left alone with tough decisions regarding their treatment. Additionally, many participants spoke about the lack of respect from the health care professionals they see. They spoke about constantly being kept waiting and then being rushed through appointments. Concerns about the varying quality and availability of services at the MS Clinics were also raised. Participants also spoke about having to travel great distances to get appropriate treatment, particularly for those in rural areas.

Our system isn't set up for chronic issues, it's focused on acute illnesses.

When you have to decide about your treatment, they give you this booklet about all the medications and tell you to read it and pick one. My neurologist told me to do my research on interferon and figure it out.

The services available are different everywhere. You have to figure it out. It is exhausting!

They should treat us as people first, not the disease.

One strong theme emerged from the discussions about health care. Every single participant believes that you have to be your own advocate to receive proper care for MS. They believe you need to be proactive, ask questions and navigate the system. The many challenges of navigating the system were talked about at great length including accessing tests more quickly, knowing who to call about symptoms, finding neurologists that provide quality and respectful care; seeking out other health care professionals who know about MS and can support you. They described the need to be able to speak up, ask questions, demand services, call around and push for what you need or want. Many of the participants expressed concern for those who are unable, either because of language or cognitive barriers, to do this and the resulting impact this would have on the quality of care they receive.

You need to be proactive and ask questions to navigate the system well. I wonder about those who don't have the wherewithal to manage or don't have family members to help.

You need to feel like you have some control. We are often treated badly. We should be treated like a customer, not a victim. There is no respect of my time. I am always kept waiting.

I am the doctor. I have to research everything. You have to be your own advocate and do your own research.

Greatest Needs

All of the focus groups concluded with a discussion regarding what programs or services the participants would like to see to help them improve their quality of life. The overwhelming response was twofold: 1) a cure for MS; and 2) an MS Hotline that would provide one point of contact for information and referrals. The participants lamented the unpredictability of their disease, the frustration and challenge of never knowing what tomorrow will bring. They spoke about how the disease itself is a barrier to quality of life. Accordingly, they said that their greatest wish is to find the cure for MS.

Sometimes I can go on a long walk with my friends and other days I can't. I would like to know what is coming around the corner – will this day be a good one or not?

I want a pill that will take this all away.

The other main request from the participants centred around system navigation. As noted previously, the challenges experienced in finding and accessing services is a significant issue for all of the focus group participants. Accordingly, every group suggested that a toll-free hotline that provides some type of system navigation or caseworker-type support would be greatly valued and improve their quality of life. There were different visions for this hotline but generally it would provide information, referrals, advice or input on quality of life programs/services that might be valuable. The participants envision this service as going beyond simple information provision in that it would help clients determine their needs or provide suggestions that they may not have asked about. Although some participants indicated they have received information from their local chapter of the MS Society, they still expressed a desire for greater support. They kept coming back to the concept of system navigation and having an expert who can help you determine what you need, then help you to find programs and services to meet that need.

I want one-stop shopping. So many services are offered by different organizations but I want to contact one person to find out about it all.

I would like a system navigator. Someone to guide me in dealing with the health care system and obtaining access to services.

I contacted my chapter and they provided me with some information. But what I really needed was someone to help me navigate the information.

Summary

While the overall tone of each focus group varied across the country, all of the groups had excellent participation. People had a lot to contribute and there was active participation from almost everyone. Participants expressed a sincere appreciation of being invited to the group and many were very impressed and grateful that the MS Society is conducting the Listening to People Affected by MS initiative. Many people expressed the sentiment that, while they have a wonderful relationship with their local Chapter, their trust and faith in the broader organization has been broken. Much of this attitude appears to be related to CCSVI as this topic came up at almost every group. While these discussions did not dominate or detract from the discussions, they were present and some expressed disappointment with the MS Society. However, the Listening Initiative is seen by most participants as a

step towards improving and repairing this relationship. Many participants indicated that they would like to see more of these types of discussions and consultations taking place. Additionally, there is a lot of interest in seeing the results of the project disseminated broadly and anticipation of the potential changes that may be seen as a result. Most participants believe that, overall their quality of life is quite good, but that more can be done to make it even better. This sense of hopefulness and optimism was present in every group. Despite the difficult discussions and heavy topic matter, the majority of participants were very positive, hopeful and optimistic about their current QOL and the future.

Appendix A
Moderator's Guides

Focus Group Moderator's Guide

Introduction

Welcome everyone and explain why we are here:

- Part of a national evaluation project called Listening to People Affected by MS that is looking at quality of life for people affected by MS
- The overall purpose of the evaluation project is to increase the MS Society's understanding of current QOL needs, priorities, gaps and barriers experienced by Canadians affected by MS
- The focus groups are one part of a larger initiative that included an on-line poll, an on-line survey and a scan of other support systems
- We are speaking with anyone affected by MS including those diagnosed with MS, those close to someone with MS and unpaid caregivers of a person with MS
- The focus group today is going to focus specifically on issues that you are facing as a person living with/affected by MS

Give confidentiality explanation – everything they say will be kept completely confidential. Their input will not be linked to their names anywhere. We are recording the discussions but only for research purposes and it will be deleted once the data has been analyzed. Somebody will be taking notes as well – again, only to support the data analysis. The notes will be destroyed once the report has been written. As participants in the group, their names will not be noted in any documentation. Have them sign the confidentiality agreement and mention that if, at any time, they would like me to turn the recorder off, we can do so.

Questions

	<p>1. Have each person say their name and briefly describe their relationship to MS. When were they diagnosed with MS? How many years has MS affected their life? What type of MS they have (if they are comfortable sharing this)?</p>
	<p>2. Let's talk about quality of life. What does quality of life mean to you? (brainstorm how they define QOL).</p> <p>Now, let's talk about how having MS affects your quality of life. Think about your day-to-day quality of life, what are the issues you deal with that relate to MS. (brainstorm all the ways it impacts QOL). Then have them think about the one thing that has the most impact on their personal QOL. Go around the room and discuss.</p>
	<p>3. What programs and services are you participating in that help you maintain a good quality of life? What programs/services are you not participating in and why not? Now let's talk about gaps in these programs. What is missing? (probe specifically re programs that encourage physical, emotional, mental and/or spiritual wellness).</p> <p>Has anyone in the room tried government programs e.g. income support, housing support, car modifications, etc.? What programs did you try? Did the program meet your needs? If not, how could it have been better suited to your needs? Has anyone tried MS Society programs? Did the program meet your needs? If not, how could it have been better suited to your needs? Probe re eligibility, application process, etc.</p>

	<p>4. We have heard from others that navigating the health care system can be very challenging especially for people with MS. There are a few areas that we want to discuss.</p> <ol style="list-style-type: none"> a. Firstly, think about when you were diagnosed with MS. Think about your interaction with the health care system at this time. What was the most difficult thing for you in dealing with the health care system at this time? (probe re neurologist, family doc., insurance provider, etc.) b. Thinking about decision-making around the treatment and management of your MS, do you feel involved in this process? Would you like to be more involved? What does that look like? c. Most of us access a number of health care services regularly, such as doctors, specialists, therapists, imaging, etc. Have you experienced any problems in accessing these types of services? Which ones are the most problematic? Under what circumstances are they a problem? d. Where do you get information about MS? Do you have enough information? Do you access the MS Society's information sources (E.g. web-site, print materials, CS staff and volunteers)? Why or why not?
	<p>5. There have probably been times when you needed specific help or support related to MS and your quality of life. Were you able to find help when you needed it? Were you able to get information about programs and services available to support you? Did you turn to the MS Society for help? What kinds of information were you looking for but did not find?</p>
	<p>6. Have any of you had issues with your workplace not accommodating any special requirements you may have relating to your MS? Please describe how they have not accommodated. What did/do you need at work to continue working?</p>
	<p>7. Where do you feel the most accommodated or supported? Where or how are your QOL needs being met? Tell me about this.</p>
	<p>8. The MS Society considers all people affected by MS to be their clients. This includes those close to someone with MS or those providing unpaid care to someone with MS. Do you think there are specific needs for these informal (family/friend) caregivers? How are they different from your needs? Does your MS affect their quality of life? Do you think caregivers receive enough support? What do they need to maintain a good quality of life?</p>
	<p>9. We hear a lot about how MS itself e.g. its symptoms, treatment, the uncertainty etc., is a barrier to a good quality of life. Part of the MS Society's mission is to improve the quality of life of people affected by MS. What do you think would help you improve your quality of life? What sorts of activities, programs, services, etc. would you like to see that would have a direct impact on your day-to-day coping and living with MS? (probe: advocacy, education, information, referral, providing programming).</p>

Caregiver Focus Group Moderator's Guide

Introduction

Welcome everyone and explain why we are here:

- Part of a national evaluation project called Listening to People Affected by MS that is looking at quality of life for people affected by MS
- The overall purpose of the evaluation project is to increase the MS Society's understanding of current QOL needs, priorities, gaps and barriers experienced by Canadians affected by MS
- The focus groups are one part of a larger initiative that included an on-line poll, an on-line survey and a scan of other support systems
- We are speaking with anyone affected by MS including those diagnosed with MS, those close to someone with MS and unpaid caregivers of a person with MS
- The focus group today is going to focus specifically on issues that you are facing as a young person living with/affected by MS

Give confidentiality explanation – everything they say will be kept completely confidential. Their input will not be linked to their names anywhere. We are recording the discussions but only for research purposes and it will be deleted once the data has been analyzed. Somebody will be taking notes as well – again, only to support the data analysis. The notes will be destroyed once the report has been written. As participants in the group, their names will not be noted in any documentation. Have them sign the confidentiality agreement and mention that if, at any time, they would like me to turn the recorder off, we can do so.

Questions

	<p>10. Have each person say their name and briefly describe their relationship to MS. Who is the person in their life with MS? How long has MS affected their life?</p>
	<p>11. Let's talk about quality of life. What does quality of life mean to you? (brainstorm how they define QOL).</p> <p>Now, let's talk about how having MS affects your quality of life. Think about your day-to-day quality of life, what are the issues you deal with that relate to MS. (brainstorm all the ways it impacts QOL). Then have them write down the one thing that has the most impact on their personal QOL. Go around the room and discuss.</p>
	<p>12. What programs and services are you participating in that help you maintain a good quality of life? Are any specifically related to MS? What programs/services are you not participating in and why not? Now let's talk about gaps in these programs. What is missing? (probe specifically re programs that encourage physical, emotional, mental and/or spiritual wellness).</p> <p>Has anyone in the room tried government programs? What programs did you try? Did the program meet your needs? If not, how could it have been better suited to your needs? Has anyone tried MS Society programs? Did the program meet your needs? If not, how could it have been better suited to your needs?</p>

	<p>13. There has been a lot of research done regarding ‘caregiver’s and the extremely difficult role this is for people who are close to someone with a chronic and debilitating illness. What are the challenges you face in this role? Do you feel you need support? Who would you like support from? What type of support do you need?</p>
	<p>14. Do you feel the health care system supports your needs a person who is close to someone with MS? Are you able to find the support you need as a caregiver? Do you have access to professional help to deal with the physical and emotional stress linked to caregiving? Would you turn to the MS Society for assistance? What kind of assistance?</p>
	<p>15. Does your workplace understand the issues you deal with as a caregiver of someone diagnosed with MS? Does your employer give you time off or flexibility as needed so that you can care for the person in your life with MS? What supports could your workplace provide that would help you as someone who is close to someone with MS?</p>
	<p>16. Has anyone used any type of respite care programs/services to allow you to have breaks from caregiving? What types of programs have you been able to access? What types of respite programs or services would be helpful to you? Would you use these services if they were available?</p>
	<p>17. Where do you feel the most accommodated or supported? Where or how are your QOL needs being met? Tell me about this.</p>
	<p>18. We hear a lot about how MS itself e.g. its symptoms, treatment, the uncertainty etc., is a barrier to a good quality of life. Part of the MS Society’s mission is to improve the quality of life of people affected by MS. What do you think would help you improve your quality of life? What sorts of activities, programs, services, etc. would you like to see that would have a direct impact on your day-to-day coping and living with MS? (probe: advocacy, education, information, referral, providing programming).</p>