



Consulting with Canadians on Flexible Work Arrangements Submission by the Multiple Sclerosis Society of Canada

The Multiple Sclerosis Society (MS) of Canada is pleased to provide this submission to the federal government's consultation on flexible work arrangements.

Introduction

As noted in the Flexible Work Arrangements - A Discussion Paper, many Canadians are *"struggling to find the right balance between their work, family, and personal responsibilities."* For people living with multiple sclerosis (MS), a chronic, often disabling disease of the central nervous system, and their caregivers, this struggle to find the right balance is amplified by a disease whose effects are physical, emotional, financial, and unpredictable and lasts for the rest of their lives. It is particularly salient in Canada as we have the highest rate of MS in the world, and it is one of the most common neurological disease affecting young adults in Canada, with most people diagnosed between the ages of 15-40 -- their prime family and career building years.

The recently published report, *MS in the Workplace* by the Conference Board of Canada, states: *"The unpredictability and episodic nature of MS make it particularly challenging in the workplace. As symptom types and severity vary greatly, individuals with MS can find it difficult to manage their treatments, let alone maintain a daily routine and meet work commitments within the traditional employment space."*¹ This aligns with the MS Society's findings from the Listening to People Affected by MS Initiative (described further below), where we heard from thousands of Canadians affected by MS about factors that impact their quality of life which included employment.

A recent review of literature published between 2002- 2011 estimated that the average unemployment rate for individuals with MS is almost 60 per cent.²

Numbers from the US indicate that people with MS experience some of the highest unemployment rates among groups of individuals with severe and chronic disabilities and have disproportionately high unemployment rates given their educational and vocational histories. Yet people with MS want to work and struggle to continue to work.³

The Institute for Research on Public Policy (IRPP) report *"Leaving Some Behind: What Happens When Workers Get Sick"*, cited as the Mowat Centre's top public policy paper in 2015, asks how Canada is doing in supporting Canadians who experience a major health issue with their employment and income needs. It points to the *"need for a comprehensive re-examination of how Canadians are able to balance work and income during periods of receiving or giving care."* The report notes that each year, six per cent of the Canadian workforce adjust its work status for some length of time in order to deal with a health condition."⁴

In general, people with disabilities face barriers in the employment context. Research conducted by the Conference Board of Canada identifies Canadians with disabilities as an under-represented group in the Canadian labour force.⁵ There are, however, substantial numbers of Canadians with disabilities that are willing and able to work. If not full-time, then at least on an intermittent basis. Certain conditions, including but not limited to, Multiple Sclerosis, arthritis, HIV, and some mental health conditions, have symptoms that are considered “episodic” – periods of good health interrupted (often unpredictably) by periods of illness or disability that affect one’s ability to work.⁶

Flexible Work Arrangements are a key tool in a person’s toolkit to continue working and maintaining quality of life.

Discussion Guide Commentary

In response specifically to the listed discussion questions, we offer the following feedback.

Women in Canada are 3 times as likely to develop MS as men, thus for Canadian women living with MS, having a disease and added family responsibilities produces even greater burden – and by extension, a disproportionate need flexible work arrangements. Furthermore, a high number of Canadians are already adjusting their work status to deal with a health condition. Greater flexibility in work arrangements is critical.

MS Society Listening to People Affected by MS Initiative

The MS Society hosted a quality of life initiative/survey in 2013 and heard from 6000 Canadians affected by MS. We heard that, in Canada, people with MS often face the reality of no longer being able to work because of the unpredictability of their disease, as well as the barriers in our support systems. The MS Society completed an environmental scan of Canadian legislation and regulations, both federal and provincial, along with the quality of life metrics of people affected by multiple sclerosis.

Canadians are legally protected from discrimination on the basis of a mental and physical disability. This applies to public transportation, taxis and buses, government offices, stores, restaurants and other business, educational institutions and other public services, as well as employment and the workplaces. Yet somehow, people applying for jobs and those who are already working are far too often evaluated by their employers on the basis of potential for difficulties based on visible symptoms or a diagnosis, rather than on their ability to carry out essential components of the job. And despite clear Charter protections, many people with MS ultimately leave the workforce because their symptoms make it too challenging to maintain full employment in a cookie-cutter setting. Needless to say, when people leaving the workforce prematurely or entirely when they ought not have to, the effects are detrimental on family income, self-esteem, and workplace productivity. We believe that stronger employer education, support systems and services should be available to enable people with MS and other chronic or episodic conditions to continue working as long as they are productive and have a desire to do so – and the solutions to get there are not radical.

Employers can accommodate episodic conditions such as MS by offering part-time work, additional breaks during the day, working mornings only, changing work tasks, and countless other collaborative solutions that retain workforce assets in the workplace while easing the challenges of the employee. There are, of course, financial implications to some of these solutions: the implication of part-time work is a reduced revenue to the employee, and many people who consider this option have seen reductions in pay, health benefits, and reduced opportunity for future short and long-term disability benefits. **These gaps need to be addressed and corrected in partnership with government.**

Types of Flexible Work Arrangements

The Multiple Sclerosis International Federation recently released its findings from a survey on employment and MS. It notes *“A diagnosis of MS shouldn’t mean someone has to give up working. Some people make a personal choice to leave employment, often due to the severity of their symptoms, or perhaps due to the perspective an MS diagnosis can bring to one’s life plans. But the truth is that many people feel they have no choice but to leave a job, even though they are willing and able to stay. **The nature of how we see ‘work’ is changing, with traditional working hours changing in favour of flexible working.** Technology makes remote working a reality and the freelance economy offers more flexible options than ever. At the same time society is beginning to recognise the work done by parents, caregivers, and volunteers.”*

Factors enabling people with MS to stay in work: Among work-related factors, seated work (38%) and flexible working hours (35%) were the two most common. Respondents with MS who were not in employment were asked what would have helped them to stay in work. The most popular factors were flexible working hours (37%) and resting time during work breaks (33%).⁷

The Multiple Sclerosis International Federation, in its *“Principles to promote the quality of life of people with MS,”* outlines a wide range of accommodations or adaptations that are possible, including part-time work, additional breaks in the work day, working only mornings, reducing the room temperature, changing work tasks, telecommuting, reducing travel, providing ramps, providing offices near restrooms, and others.⁸

All of the potential tools mentioned in the discussion guide could and would make a positive difference in people’s lives if implemented system-wide. These include: flexibility in the number of hours worked, flexible location of work, flexible leaves, and flexibility in rest periods.

Employers

The IRPP report highlights the role employers can play including having flexible working arrangements: *“In addition to supports provided by a private insurance carrier or a public benefit program, employers also have an important role to play in helping accommodate workers. Often these accommodations, which can include such things as flexible work hours or assistive devices, are relatively inexpensive to implement. What is required is effective awareness of potential needs, understanding of the types of job accommodations that might be beneficial, and a commitment to practice.”*⁴

The study further notes that *“Providing active employment supports for both employers and workers earlier on in the course of an illness may help improve the well-being of workers as they recover from an illness, enhance earnings capacity, raise long-term employment retention, and, as a result, potentially reduce the need for future claims.”*⁴

In terms of the benefits to employers of supporting employees, discussion in the IRPP report notes that there is an emerging body of research that employer supports are demonstrating long term benefits to employers relating to turnover and related costs.⁴ The Conference Board paper also highlights that supportive workplaces with positive employer attitudes and suitable accommodations like flexible working arrangements can lead to greater employee retention and for employers this can reduce turnover and be beneficial by retaining skills and experience of their employees.¹ All these findings point to the conclusion that not dealing with people living with MS (and other episodic conditions) is worse for the economy, worse for productivity, and a heavier burden on state supports than would be the case if we enhanced collaborative solutions to promote flexible work arrangements.

Caregivers

Employees and employers are not the only stakeholders in this discussion. In considering policy framework options, it is important to also understand and support the caregivers of those with chronic and episodic conditions.

Caring for a person with MS can have an impact on the caregivers' employment in a similar way to living with the illness directly. The IRPP report acknowledges the important role of these caregivers: *"Just like those who are sick, job protection, flexible work arrangements and income replacement while on leave are critical for helping caregivers balance their work and care responsibilities. In practice, many employers have begun to provide various accommodations to address the rising pressure of care-giving responsibilities among workers (ESDC 2015b). As has been noted by the recent federal Employers Panel for Caregivers, the business case for doing this is potentially strong: taking proactive steps to plan for and address these needs can help to reduce lost productivity and even increase employee loyalty."*⁴

The Conference Board of Canada's recent report *"Multiple Sclerosis in the Workplace: Successful Employment Experiences"* notes that the 2014 federal Employer Panel for Caregivers by the Minister of State for Seniors' mandate was to engage with employers to identify best practices for supporting employee caregivers and to share these findings with Canadian stakeholders. One of the insights from the Employer Panel's report was that employers were generally aware of the trend toward informal care, but were not aware of the magnitude. Informal care already affects 35 per cent of the Canadian workforce.¹

Another insight was that most employers addressed needs of employee caregivers on more of a case-by-case basis, with the most frequent supports being flexible work hours and the use of communication technology. It also notes that small business employers may have more challenges in providing flexible, supportive options to help their employees retain employment. Employers could allow caregivers the option of flexible work arrangements that allow them to care for loved ones with MS. These may minimize the likelihood of a caregiver reducing his or her workload or leaving the workforce altogether.¹

Awareness, Communication and Education

We cannot stress enough the importance of collaboration between all parties in facilitating optimal outcomes. The best way to promote workplace participation, and to adapt solutions and supports, is to work on a case-by-case basis and assess each specific situation, develop a plan with the employee with MS, and to communicate with other employees to promote awareness.

The employee also has an important role to play in this process. Disclosing a diagnosis and educating an employer about the impact of MS is often the first step toward managing employment-related issues. In many cases, fear, uncertainty, judgment from coworkers and the potential stigma associated with MS may deter people from making this disclosure, and all stakeholders have a role to play in breaking down these barriers, and promoting tolerance and acceptance.

Conclusion

We applaud the government for consulting with Canadians about flexible work arrangements. As discussed above, greater flexibility and creative collaborative solutions are: better for the economy; better for the employer and better for the employee. Numerous studies bear this out. In fact, they all point to similar conclusions that employers, employees (including caregivers) and government all have an important role to play in implementing this. Having employers be open to flexibility and working collaboratively with the employee; allowing partial and intermittent work schedules; exploring insurance/benefit and public programs that fill any gaps that may emerge from flexible solutions; promote awareness in the workplace to facilitate transition to flexible work arrangements; and consider caregivers as well. For employees including caregivers it is important to be proactive with employers to find solutions that meet the needs and reduce challenges faced by employees and create optimal lead time in cooperative solution making.

The Federal Government's role and first step is bringing forward the legislation discussed to amend the Canada Labour Code to allow workers in federally regulated sectors to formally request flexible work arrangements from their employers as the Prime Minister has mandated the Minister of Employment, Workforce Development, and Labour, the Honourable MaryAnn Mihychuk to do. It will also be important to expand this to both provincially regulated sectors and into the private sector, so Flexible Work Arrangements becomes used widespread in workplaces for all Canadians.

About The Multiple Sclerosis Society of Canada

The mission of the MS Society of Canada is "to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life." The MS Society provides programs and services including information, support, education, wellness and other resources for people with MS and their families.

We believe a future free of MS is achievable. We have contributed over \$150 million towards MS research since 1948. Our research investment has enabled Canada to create a pipeline of exceptional MS researchers and become a leading contributor to discovery in the field of MS.

Along with our members, volunteers and staff, we work to ensure Canadians living with MS and their families have the opportunity to participate fully in all aspects of life by advocating for improvements in government legislation and policies, private industry practices and/or public attitudes.

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¹ Thy, Dinh, Philip Astles, and Karen Turpin. *Multiple Sclerosis in the Workplace: Supporting Successful Employment Experiences*. Ottawa: The Conference Board of Canada, 2016.

² Schiavolin, S., and others. "Factors Related to Difficulties With Employment in Patients With Multiple Sclerosis: A Review of 2002–2011 Literature." *International Journal of Rehabilitation Research* 36, no. 2 (2013):105–111.

³ Sweetland, J., Howse, E., & Playford E., *Disability & Rehabilitation*, 2012; 34(24): 2031-2038.

⁴ Meredith, T., and Chia, C. *Leaving Some Behind: What Happens When Workers Get Sick*. Institute for Research on Public Policy, 2015.

⁵ Brisbois, Richard. *Business Benefits of Accessible Workplaces*. Ottawa: The Conference Board of Canada, 2014.

⁶ Smith Fowler, H., *Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario?* (accessed 17 March 2016) available from http://www.srdc.org/uploads/IntermittentWork_report_EN.pdf

⁷ Multiple Sclerosis International Federation, *Global MS Employment Report 2016* (accessed 22 June 2016) available from <http://www.msif.org/wp-content/uploads/2016/05/Global-MS-Employment-Report-2016.pdf>

⁸ Multiple Sclerosis International Federation, *Principles to Promote Quality of Life* (accessed 22 June 2016) available from <http://www.msif.org/about-us/advocacy/principles-to-promote-quality-of-life/#sthash.SJNsWzU3.dpuf>