Multiple Sclerosis in the Workplace.
Supporting Successful Employment Experiences
Multiple Sclerosis in the Workplace: Supporting Successful Employment Experiences
Thy Dinh, Philip Astles, and Karen Turpin

Preface
The Conference Board of Canada was asked to examine the issues that affect individuals with multiple sclerosis (MS)—and their caregivers—from an employment perspective. The main objective of this report is to discuss these issues and to propose recommendations that can better support individuals with MS and their caregivers. This support would enable more successful participation in the labour force and a better quality of life. Specifically, the aim of this report is to provide high-level understanding of the MS experience in Canada as it relates to employment, and describe the relative success of treatments and strategies to mitigate the impacts of the disease in the workplace. This includes potential actions that can be taken by employees, employers, governments, and other stakeholder groups.

The information and insights in this report were derived from two main phases of research. In the first phase, a review of the literature and consultations with a group of experts (the steering committee) culminated in a discussion guide that was used as the basis for the second phase. The second phase involved a facilitated stakeholder workshop held in late 2015. This workshop brought together individuals with MS, caregivers, health and social services providers, and provider organizations, researchers, insurers, and employers to discuss the research topic and add to the insights from the initial phase.


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Acknowledgements

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EXECUTIVE SUMMARY

Multiple Sclerosis in the Workplace: Supporting Successful Employment Experiences

At a Glance

• Productivity loss in individuals living with multiple sclerosis (MS) may account for about one-third of the total economic burden of MS.

• Positive employer attitudes and accommodations for employees with MS can lead to financial and health benefits for employees, while also increasing skilled worker retention and productivity.

• Individuals with MS can benefit from the early use of interventions and disease management strategies that can mitigate or prevent the impacts of the disease on their quality of life and employment.
Increased workforce participation by individuals with multiple sclerosis (MS), and their caregivers, can represent a win-win-win for those individuals, their employers, and the government. Appropriate use of therapeutic interventions may have a positive impact on such participation and quality of life (QoL) in general. In addition, better and more coordinated employer and government supports could further increase workforce participation by removing barriers for those who have the capacity and desire to work.

There are approximately 68,000 women and 25,000 men in Canada with MS, representing about 300 cases per 100,000 people.¹ MS can be diagnosed at any age; however, onset usually occurs during a person’s most employable period of life—between 15 and 40 years of age.² Of those diagnosed with MS, many reduce the amount of paid work they do, or become unemployed. The cost of the productivity loss, including unemployment and reduced working, has been estimated to account for 33 per cent of the overall economic burden of MS and 47 per cent of increased costs when a relapse has occurred.³,⁴ In Canada, this overall cost could be anywhere between $260 million and $2.8 billion, depending on which indirect costs are included and how they are calculated. This makes MS a significant economic issue for individuals with MS and for their employers.

¹ Statistics Canada, CANSIM table 105-1300. Note: This does not include people with MS in long-term care, or increases since 2010.
² Multiple Sclerosis Society of Canada, About MS.
³ Oleen-Burkey and others, “Burden of a Multiple Sclerosis Relapse,” 57–69.
Those employees who leave the workforce due to their own MS—or their caregiving commitment to someone else with MS—can encounter many obstacles should they try to re-enter the workforce. This is important because, in addition to income, employment affords individuals a sense of purpose, dignity, and social connectivity, which impacts their overall quality of life.

The symptoms of MS that are most associated with people leaving work include fatigue, anxiety, depression, pain, and cognitive difficulties. In addition to the direct challenges that these symptoms pose, the often-fluctuating severity and episodic nature of MS create further challenges in the workplace and the ability to receive appropriate supports. Although there is currently no cure for MS, many interventions are available to help limit the impact of the disease on QoL and employment. For example, some drugs for MS can reduce the likelihood and severity of relapse while slowing the overall progression of disability.

Although traditional research on MS drug therapies has appropriately focused on symptoms and disease progression, this has been extended, in a few cases, to include workplace productivity as an outcome. The productivity benefits of some drug treatments have been found to include more working hours, greater ability to cope with work requirements, greater disease stability, and reduced sick leave. These and non-productivity benefits can be greater if treatment is commenced early in the course of the disease. Other therapeutic approaches—including physiotherapy, neuropsychological rehabilitation, mindfulness-based

6 Multiple Sclerosis Society of Canada, The Cost of Caring.
7 Bevan, and others, Ready to Work.
8 Johnson and others, “Medical, Psychological, Social, and Programmatic Barriers,” 38–49.
9 Canadian Institute for Health Information, Canadian Multiple Sclerosis Monitoring System.
12 Wickstrom and others, “Reduced Sick Leave in Multiple Sclerosis,” 1095–1101.
Through appropriate workplace accommodations, employers can increase the retention of experienced workers.

Interventions, and mental health support programs—are also being used to treat the symptoms of MS. The potential of these non-drug therapies to benefit people with MS could be further revealed by more research.

As well as the therapies that are aimed at reducing the severity, frequency, or progression of MS symptoms, coping strategies that are developed through workplace adaptation or vocational rehabilitation frameworks can also play a role in enabling individuals with MS to remain employed. According to the Multiple Sclerosis Society of Canada, many individuals with MS who leave employment say that they would have stayed longer if appropriate modifications had been made to their work requirements or physical environment.13

To achieve these workplace modifications, employers and employees must work together to find a solution that benefits both parties. One of the challenges of workplace modifications is a traditional focus on addressing “visible disabilities.” These measures need to be complemented with more efforts to address “invisible disabilities” associated with MS—such as fatigue, depression, pain, and cognitive symptoms—as well as recognition of the often episodic nature of the disease. Planning and approaches to workplace adaptation and accommodation would benefit from a greater appreciation of the symptoms and needs of employees with MS.

Our insights suggest that by creating an open and positive culture regarding MS, employers can encourage employees to actively communicate their diagnosis at the early stages of the disease. Through appropriate workplace accommodations, employers can increase the retention of experienced and skilled workers and optimize their productivity. Supporting individuals with MS, and also their caregivers, to realize full employment potential will benefit not only individuals’ well-being (financially and health-wise) but also that of society. From the government’s perspective, increasing access to disability programs, and financial benefits and supports for those with MS and their caregivers, is essential.

13 Multiple Sclerosis Society of Canada, MS in the Workplace: An Employer’s Guide.
CHAPTER 1

Introduction

Chapter Summary

- Decreased workforce participation from people living with multiple sclerosis is often detrimental to the health and financial situation of individuals and also has a large overall economic impact due to lost productivity.

- The objective of this research is to identify approaches that stakeholders can use to support a better quality of life (QoL) and champion successful employment for people living with MS, and for their caregivers.

- Although many organizations have embraced diversity, people with disabilities continue to be overlooked in the labour force, and their talents are wasted by companies not employing or under-employing these qualified individuals.
What Is MS?

Multiple sclerosis (MS) is a chronic progressive disease that affects the central nervous system, which consists of the brain, spinal cord, and optic nerves. The spectrum of MS may vary from mild to severe, with increasing disability and loss of physical and cognitive functions.\(^1,2\) Although the cause or causes of MS are still largely unknown, scientists believe that there are several genetic and environmental factors, and their interactions may be associated with the onset of the disease.\(^3\) Much more research is needed to understand the disease and the risk factors associated with its development.

In terms of the clinical course of disease, MS is characterized most often in four disease categories. The following descriptions of these categories were taken from Lubin.\(^4,5\) The most common forms of MS are characterized by acute symptoms or attacks called “relapses” and periods of recovery in between called “remissions,” at which time the individual will experience no or few symptoms. Relapses can last from a day to weeks or months, while remissions can last a year or more. The unpredictability and frequency of relapses experienced by many individuals with MS has characterized the disease as an episodic

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4. Although this was a revised document by the same authors, the definitions for the MS disease categories remained the same as those published in 1996.
5. Lublin and others, “Defining the Clinical Course of Multiple Sclerosis,” 278–86.
condition. The episodic nature of MS poses challenges in relation to the availability and quality of support services that tend to be more widely available for individuals with chronic disabilities.

A person with relapsing-remitting MS (RRMS) is described as having clearly defined episodes of acute worsening of neurological function, with recovery or remission and stable courses between relapses. RRMS is the most common type of MS, with 85 per cent of the MS population having this or the form it progresses to—secondary-progressive MS (SPMS). A person with SPMS is described as previously having RRMS and experiencing gradual neurologic deterioration with or without acute relapses. The likelihood of a person with RRMS developing SPMS increases with time (32 to 40 per cent after 10 years, and up to 90 per cent after 25 years). Less common are primary-progressive MS (PPMS) and progressive-relapsing MS (PRMS), which account for 10 and 5 per cent of cases, respectively. A person with PPMS is described as having gradual, nearly continuous, neurologic deterioration from the onset of symptoms, with no distinct relapses. PRMS is a rare form of MS and is described as a progressive disease from onset, with clear acute relapses, with or without full recovery, and with periods between relapses, characterized by continuing progressive neurologic deterioration.

Table 1 is an overview of the most common symptoms of MS as described by the European MS Platform. Although MS symptoms can be numerous and debilitating, many individuals with MS have symptoms that can be effectively managed and, as a result, these people can still resume or obtain meaningful employment. Approaches to effectively managing symptoms so that individuals with MS can stay employed or obtain employment are elaborated in the insights section of this report.

6 Multiple Sclerosis Society of Canada, *About MS.*
7 Goodin, *Multiple Sclerosis and Related Disorders.*
8 Multiple Sclerosis Society of Canada, *About MS.*
9 European Multiple Sclerosis Platform, *Consensus Paper.*
Table 1
The Most Common Symptoms of MS

<table>
<thead>
<tr>
<th>Symptom category</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor function and coordination</td>
<td>Muscle tightness, muscle weakness, loss of full control of bodily movements, tremors</td>
</tr>
<tr>
<td>Cranial nerves</td>
<td>Double vision, rapid involuntary eye movement, speech impediments, difficulty swallowing</td>
</tr>
<tr>
<td>Autonomic nervous system function</td>
<td>Bladder dysfunction, bowel dysfunction, sexual dysfunction</td>
</tr>
<tr>
<td>Psychiatric and psychological problems</td>
<td>Depression, disturbances of cognitive function, fatigue</td>
</tr>
<tr>
<td>Pain and sudden/intense symptoms</td>
<td>Seizures, trigeminal neuralgia, Lhermitte's sign</td>
</tr>
</tbody>
</table>

Note: Many individuals living with MS can experience onset or exacerbation of one or more of the above symptoms if their core body temperature increases. This is referred to as heat intolerance. Source: European Multiple Sclerosis Platform, Consensus Paper.

Challenges in the Workplace

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. Also, the challenges in the workplace faced by caregivers of individuals with MS are seldom considered.

A recent review of literature, published between 2002 and 2011, estimated that the average unemployment rate of individuals with MS is almost 60 per cent. This finding summarized 24 unemployment estimates of people with MS from European and North American countries (including two estimates from Canada: 61 per cent and 48 per cent).

11 Honamand and others, “Predicting Employment Status in Multiple Sclerosis Patients,” 244–49.
People with disabilities continue to be often overlooked in the labour force.

All of the studies included specific data on self-reported, work-related difficulties. The population of 32.5 thousand people included in the studies had a mean age of 46.2 years and 71 per cent were female. The proportion of the population who had RRMS was 42 per cent.

The review found that younger people, and those with higher educational qualifications, had a greater chance to be employed. In addition, the review found that the inability to work was increased in those who had MS for longer, and who experienced more severe symptoms. The symptoms most frequently reported as being linked to employment were fatigue, mobility problems, and cognitive difficulties. Many employees who have MS, or who are the employees’ caregivers, end up leaving the workforce in part or altogether. In addition, people living with MS may face many challenges if they attempt to re-enter the workforce.13,14

There is a need to understand the impact of MS on employees (individuals with MS and their caregivers) and their employers. It is also necessary to develop multi-sectoral recommendations that can be implemented to better support the QoL, employment, and advancement of Canadians with MS.

Previous Conference Board research has identified Canadians with disabilities as an under-represented group in the Canadian labour force.15 Although many organizations have embraced diversity, people with disabilities continue to be often overlooked in the labour force. When this occurs, their talents and potential may be missed by companies not employing or under-employing these qualified individuals.

12 Busche and others, “Short Term Predictors,” 137–42.
14 Multiple Sclerosis Society of Canada, The Cost of Caring.
15 Brisbois, Business Benefits of Accessible Workplaces.
Businesses cannot afford to ignore such a large segment of Canada’s labour force. At the same time, the aging of the labour force will lead to increased rates of disabilities for many existing mature workers. Basic accommodations can often extend the careers of this valuable talent pool and should be a priority for employers.\textsuperscript{16}

Based on the Multiple Sclerosis International Federation (MSIF) 2013 study, it can be seen that in comparison with many other countries—including the U.S.—Canada does not have workplace entitlements specifically designed for employees living with MS. These benefits include relocation, flexible working situations, and early retirement. (See Exhibit 1.) This does not include a wide range of services related to employment in which Canada may perform relatively well, such as available training or employment advice. The entitlements also do not include other benefits that are not directly related to employment—such as housing, transportation, rehabilitation, and tax or other monetary benefits.

\textbf{Exhibit 1}
\textit{Atlas of MS, 2013—Benefits in the Workplace, Globally}
(benefits in the workplace; e.g., relocation, flexible working situations, early retirement.)

Source: Multiple Sclerosis International Federation.

\textsuperscript{16} Ibid.
Likely, this is because the same study found that these entitlements are included in legislation dealing with disabilities more generally. What we will come to realize, however, is that individuals with MS do not necessarily meet the requirements to be categorized as “disabled” in Canada and are challenged in accessing the benefits they need.17 This observation applies not only to workplace disability benefits for individuals with MS, but also to all other benefits—including monetary compensation (pension/allowance); tax benefits; rehabilitation and health benefits; and benefits in the home (adaptations, living aids, homecare, etc.).18 It seems illogical that even though Canada has the highest prevalence of MS in the world, it lags other countries in specifically designing entitlements for MS. Later in this report, we further discuss the challenges of how institutional definitions of disability apply to individuals living with MS.

Employment provides people with the opportunity for income, a sense of purpose, dignity, and social connectivity.19 Without it, individuals with MS are vulnerable to economic hardship, social exclusion, and reduced self-confidence and self-efficacy.20 Individuals with MS who are willing and able to work certainly can do so as long as the proper supports are in place. The supports enable these individuals to not only be part of the labour force, but to do so effectively.

**The Focus of This Research**

The specific objective of this work by the Conference Board, through a program of research and dialogue, is to identify approaches that stakeholders can use to support better QoL and champion successful employment for individuals living with MS, and for their caregivers. The primary outcome of interest in this research is improved QoL, resulting from better employment experiences for these target populations.

18 Multiple Sclerosis International Federation, *Atlas of MS 201: Epidemiology of MS.*
19 Bevan and others, *Ready to Work.*
The most effective and sustainable approaches to improving employment among individuals with MS and their caregivers are multi-sectoral interventions: for example, better access to effective medical and non-medical therapies, better access and availability of social and support services, as well as appropriate economic policies.

These and other interventions can help individuals with MS effectively manage their disease—including symptoms—and improve QoL, as well as allow them and their caregivers to remain in the workforce.

The Health and Economic Burden of MS in Canada

According to data from the 2000–01 and 2010–11 Canadian Community Health Survey (CCHS) cycles, MS is becoming more common in Canada.\(^{21,22}\) In addition, it can be seen from the MSIF *Atlas of MS*, which uses survey data collected from October 2012 to June 2013, that Canada has the highest rate of MS compared with the 40 other countries in the survey.\(^{23}\) (See Exhibit 2.) Although the Atlas presents rates that are lower than those estimated from the most recent CCHS data,\(^{24}\) it does show that the rate of MS in Canada is almost two times higher than in the U.S. (the country with the second-highest number of cases, at 135 cases of MS per 100,000 population).

Within the high, overall prevalence in Canada, there is a great deal of variation between provinces. (See Table 2.) It should be cautioned that as prevalence may change over time (as Kingwell and others show in the province of British Columbia), differences in the year in which provincial estimates were taken limit comparability between them.

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21 Statistics Canada, CANSIM table 105–1300. Note: This does not include people with MS in long-term care.
22 Beck and others, “Regional Variation of Multiple Sclerosis,” 516–19.
24 The rate of 240 per 100,000 population was reported in the Atlas likely because the only data available at that time were estimates from the CCHS from 2000–01.
Of the Canadian provinces, the lowest prevalence estimate was reported in Newfoundland and Labrador (about 94 per 100,000 population) and the highest rates were in the Atlantic provinces (combined) and Alberta (about 350 per 100,000 population). From a closer look at the data, however, it can be seen that the high prevalence in Atlantic Canada, overall, is apparent despite the markedly lower prevalence in two of the Atlantic provinces: Newfoundland and Labrador and Nova Scotia.

This suggests that prevalence in one or both of the other provinces for which there are no data (Prince Edward Island and New Brunswick) must be higher than 350 per 100,000. On a more global scale, the prevalence of MS tends to increase with distance from the equator.

MS poses a significant health burden to individuals affected by the condition. Although it can occur at any age, onset usually appears during a highly productive period of life—between the ages of 15 and 40.

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Table 2
MS Prevalence in Canadian Provinces and Regions
(per 100,000 population)

<table>
<thead>
<tr>
<th>Province or region</th>
<th>Crude prevalence</th>
<th>Age-adjusted prevalence</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Columbia</td>
<td>240</td>
<td></td>
<td>2000–01</td>
</tr>
<tr>
<td>Alberta</td>
<td>358</td>
<td></td>
<td>2004</td>
</tr>
<tr>
<td>Saskatchewan*</td>
<td>298</td>
<td>329</td>
<td>2004</td>
</tr>
<tr>
<td>Manitoba</td>
<td>261</td>
<td>262</td>
<td>2006–07</td>
</tr>
<tr>
<td>Prairies</td>
<td>340</td>
<td></td>
<td>2000–01</td>
</tr>
<tr>
<td>Ontario</td>
<td>230</td>
<td></td>
<td>2001</td>
</tr>
<tr>
<td>Quebec</td>
<td>180</td>
<td></td>
<td>2000–01</td>
</tr>
<tr>
<td>New Brunswick</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>267</td>
<td>267</td>
<td>2010</td>
</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>94</td>
<td></td>
<td>2001</td>
</tr>
<tr>
<td>Atlantic Canada</td>
<td>350</td>
<td></td>
<td>2000–01</td>
</tr>
<tr>
<td>Nunavut</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northwest Territories</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yukon Territories</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>240</td>
<td></td>
<td>2000–01</td>
</tr>
</tbody>
</table>

*Estimate for Saskatoon only.
Sources: Evans and others, "Incidence and Prevalence of Multiple Sclerosis in the Americas" (excluding Nova Scotia); Marrie and others, "The Incidence and Prevalence of Multiple Sclerosis in Nova Scotia, Canada."

years. The many different symptoms that individuals may experience over the course of the disease can significantly impact their QoL. The inability to manage MS symptoms effectively can have a negative impact on an individual’s capacity to perform the daily tasks of living, gaining and retaining employment, or participating in social activities. In terms of mortality and life expectancy—although the long-term accumulation of severe disability is not usually the direct or immediate cause of

27 Multiple Sclerosis Society of Canada, About MS.
premature death—individuals living with MS have a significantly higher mortality rate than those in the general population (a difference of 7 to 14 years of life expectancy).28 A recent Canadian study found a similar magnitude of reduced life expectancy for people living with MS (eight years less). These effects (disability and premature mortality) can result in economic and social deficits experienced by the individuals themselves, their caregivers, and society as a whole.

At the individual level, the full economic burden of MS includes out-of-pocket expenses for treatments, transportation, assisted living, and other supports. The inability to obtain or retain employment contributes to a lack of financial resources to cover these expenses, especially when social welfare programs are unavailable or inadequate. Loss of income can also be experienced by caregivers of individuals with MS due to the demands of that role. Many families with a member affected by a neurological condition such as MS may undergo a financial crisis.29 When individuals with MS and their caregivers are unable to realize their full employment potential, the economy suffers through lost productivity. (See “Tackling the Challenges of MS.”)

A study by Oleen-Burkey and others found that individuals with MS who experience relapse have significantly higher annual direct and indirect costs compared with those who do not experience relapse.30 In this study, indirect costs included informal care as well as productivity losses, accounting for almost 50 per cent of the total indirect cost.

According to a report by the Public Health Agency of Canada, Economic Burden of Illness in Canada, 2005–2008, MS was estimated to have a total annual economic burden of $260 million in 2008.31 This value includes the direct costs to the health care system, including hospital, physician, and drug costs; and indirect costs to society by way of lost productivity due to premature mortality.

28 Scalfari and others, “Mortality in Patients With Multiple Sclerosis,” 184–92.
29 Neurological Health Charities Canada, National Population Health Study.
Previously reported estimates of the cost of MS, based on a report by the Canadian Institute for Health Information (CIHI) for the year 2000–01, indicated that the economic burden of MS was about $1 billion annually.\textsuperscript{32} The large discrepancy in values can be explained by the differences in the way indirect costs were calculated. In the newer numbers (2008), indirect costs are only 1 per cent of the total cost of MS. In the older numbers (2000), indirect costs constituted the overwhelming majority of the costs. The older method used the human capital approach to account for indirect costs, which added up (in mortality costs) to the net present value of foregone future income for each person dying from MS. For example, if someone with MS died at the age of 50, all future income that individual would have earned, had they stayed alive, would have been counted in the indirect (mortality) costs. Within the lower estimate from PHAC in 2008, some small costs are added—namely the cost to replace that individual at work, but not his or her future income. This explanation also applies to the differences in disability costs (foregone income due to disability versus replacement costs).

Another Canadian estimate from 2011 found that the mean cost per person with MS was over $37,000.\textsuperscript{33} Using this figure plus estimates of the size of the MS population quoted in the study (55,000–75,000 people) resulted in an estimated annual cost of MS in Canada of between $2.1 and $2.8 billion. This cost included both direct and indirect costs, with direct health care costs accounting for 46 per cent of costs, while sick leave and retirement accounted for 32 per cent. Costs varied significantly depending on disease severity and the occurrence of relapse. This and the other estimates may be missing an important, but unquantifiable component of costs. That component is the intangible costs associated with reduced QoL for persons with MS, their family, and their friends.\textsuperscript{34}

\begin{itemize}
  \item \textsuperscript{32} Canadian Institute for Health Information, \textit{The Burden of Neurological Diseases}.
  \item \textsuperscript{33} Karampampa and others, “Treatment Experience, Burden, and Unmet Needs (TRIBUNE).”
  \item \textsuperscript{34} Trisolini and others, “Global Economic Impact of Multiple Sclerosis.”
\end{itemize}
Tackling the Challenges of MS Requires a Paradigm Shift

While much public, media, and policy attention has focused on treatments to manage MS, the critical aspect of adequate support for individuals with MS—specifically, access to information and strategies to effectively manage symptoms of the disease—are less prominent. However, the MS Society of Canada does provide resources in this area. More pressing is the need for more appropriate supports related to income and employment, and resources for caregivers of individuals with MS, as they too face a burden that can affect them economically and health-wise. A broad strategy to improve the QoL for Canadians with MS and their caregivers is absent.

A notable exception is Alberta. In 2013, the province—through Alberta’s MS Partnership—created The Way Forward, a comprehensive MS strategy and vision that focuses on QoL, collaboration, and five recommendations to guide actions.35 These recommendations are:

• provide comprehensive and integrated services;
• coordinate disability supports across sectors, ministries, and government levels;
• support empowerment and self-management;
• develop education, awareness, and general capacity within their systems to support Albertans with MS;
• advance MS research and evaluation.

Alberta’s MS Partnership includes the MS Society of Canada (Alberta and Northwest Territories Division); the Calgary, Edmonton, and Red Deer MS clinics; the University of Alberta; the University of Calgary; Alberta Health Services; Alberta Human Services; and Alberta Municipal Affairs. The Alberta example is one aspect of a paradigm shift that would benefit individuals with MS in their daily lives. Achieving this change in mindset would enable Canadians with MS and their caregivers to integrate more fully into the mainstream of society, including the workplace.

CHAPTER 2

Insights From a Review of the Literature

Chapter Summary

• Research has found that employees who actively communicated their diagnosis to their employer were more likely to be employed, and for longer periods of time.

• Many individuals with MS who stopped working said that they would have continued for longer if there had been adjustments to their work requirements or to their physical environment.

• Many successful interventions are available for MS. These can be used to reduce the severity and impact of symptoms, especially if accessed early in the onset of the disease.

• In Canada, one of the greatest challenges faced by caregivers is the inability to find the supports, financial or otherwise, they need for themselves or to assist them in caring for their loved ones.
Literature Review Methodology

The approach to generating insights and knowledge for this report included a literature review that followed a systematic review protocol format. A PICO process (identifying population, intervention, comparison/control/comparator, and outcomes) was used to identify relevant research documents. Given that this literature review did not require as intensive a process as a full systematic review, certain liberties were taken in order to speed the review process while producing high-quality results. The detailed methodology is described in Appendix A.

The subsequent section of this report is a synthesis of information from selected research, taken from the review. Published and unpublished information that was the most recent and relevant to the objectives of the review was more likely to be referenced. Under the insights section, this report focuses on best approaches or interventions to better support individuals with MS and their caregivers, so that they may ultimately realize successful employment. Although not all eligible studies were included, a full bibliography of all resources that were available at the eligibility review stage is shown in Appendix C. We included quantitative statistics from Canadian administrative and survey databases/datasets, such as the Economic Burden of Illness in Canada, the Canadian Community Health Survey, and the General Social Survey, to further provide contextual understanding. Some of these data were included in Chapter 1.

It is important to note that the Conference Board worked with the steering committee to develop the literature review search strategy. The steering committee, made up of content experts, was also asked to identify sources of information and documentation to be included in the
Symptoms and disabilities affect not only early leave from work but also presenteeism.

review, particularly in terms of the “grey” (unpublished) literature. The steering committee also reviewed, and commented on this report and the discussion guide that it is derived from.

Success in the Workplace

As mentioned in Chapter 1, it has been estimated that the average unemployment rate of individuals with MS is almost 60 per cent, and this tends to increase as the disease progresses. Work is important to an individual not only financially, but also because of other associated benefits that include social connection, QoL, and self-esteem.

Factors that lead to unemployment for individuals with MS include disease-related factors such as relapses, symptoms, and resulting disabilities that make it difficult for individuals to be at work and often cause people to leave employment. Relapses can be undermining to employees with MS, causing them to lose confidence in their ability to work effectively. Symptoms that have the greatest impact on people leaving employment include fatigue, anxiety, and depression. Other symptoms that have an important impact on employment include pain, heat intolerance, memory and concentration difficulties, verbal fluency, information processing speed and cognitive flexibility, mobility limitations, poor dexterity, visual impairment, and urinary and bowel dysfunction.

All of these symptoms and disabilities affect not only early leave from work but also presenteeism, which is the “action of employees coming to work despite having a sickness that justifies an absence. And, as

1 Schiavolin and others, “Factors Related to Difficulties With Employment,” 105–11.
2 Waddell and Burton as cited in Doogan and Playford, “Supporting Work for People With Multiple Sclerosis,” 646–50.
5 Johnson and others, “Medical, Psychological, Social, and Programmatic Barriers,” 38–49.
6 Ibid.
7 Simmons and others, “Living With Multiple Sclerosis,” 926–36.
Effective management is a combined effort between employers and employees.

a consequence, they are performing their work under suboptimal conditions.9 The effective management of these symptoms early on in the course of the disease is important for individuals with MS to be able to be, and remain, productive in the workplace. Effective management is not solely the responsibility of the individual, but rather a combined effort between employers and employees. Management includes not only timely access to appropriate treatments and therapies, but also adaptations to working environments, work demands, and other workplace factors such as accommodation and access to information. In addition, the health care system and governments can play a facilitative role in helping individuals with MS access treatments, health and social services, and other resources available to them and their caregivers so that they can be more successful in the workplace.

Many individuals with MS who stop working say that they would have continued for longer if there had been adjustments to their work requirements or physical environment.10 This assertion is supported by results from a survey conducted for the MS Society of Canada in 2012–13.11 In that survey, only half of respondents indicated that their workplace had made changes so that they could work despite their MS. A partnership between employees with MS and their employers is essential to achieving a working arrangement that benefits both parties. This initially requires employees to take the important and often difficult step of actively communicating their diagnosis.12 This difficulty may stem from a fear of harassment, employment termination, or other discrimination,13 and also possibly from a desire for privacy. However, once employees communicate their diagnosis, it is important that it is met with a positive response by their employer. Although not guaranteed, recent studies have found that a positive response was given by the

10  Multiple Sclerosis Society of Canada, MS in the Workplace: An Employer’s Guide.
11  Multiple Sclerosis Society of Canada, Listening to People Affected by MS.
12  The process of actively communicating a diagnosis of MS is sometimes referred to as “disclosure.”
13  Frndak and others, “Disclosure of Disease Status Among Employed Multiple Sclerosis Patients.”
majority of employers.\textsuperscript{14,15} This is encouraging because poor employer attitude has been noted as a potential explanatory factor in the high unemployment rate of individuals living with MS.\textsuperscript{16} A notable initiative in this area is the European Employment Pact for People With Multiple Sclerosis.\textsuperscript{17} This aims to motivate business leaders to demonstrate their commitment to creating a healthy workplace for all staff, including those with MS. It emphasizes that people with valuable business assets in terms of education, skills, and experience can be excluded from the workplace unnecessarily, due to lack of understanding and prejudice.

**Disability and MS**

According to the World Health Organization, disability is described as an “umbrella term, covering impairments, activity limitations, and participation restrictions; where impairment is a problem in bodily function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.”\textsuperscript{18} This definition includes the recognition that disability is a reflection of the interaction between the features of a person’s body and the physical and social environment in which they live. Thus, disabilities can sometimes be overcome by altering the environment.

Individuals living with MS have been described as experiencing “disability trajectories” that may cause them to be perceived and treated as being “too disabled” to be successful in the workplace but “not disabled enough” to receive certain disability social programs and

\textsuperscript{14} Kirk-Brown and others, “Disclosure of Diagnosis of Multiple Sclerosis in the Workplace,” 162–32.

\textsuperscript{15} Frndak and others, “Disclosure of Disease Status Among Employed Multiple Sclerosis Patients.”


\textsuperscript{17} European Multiple Sclerosis Platform, European Employment Pact.

\textsuperscript{18} World Health Organization, International Classification of Functioning.
benefits. For example, the first question on the eligibility questionnaire for disability tax credit (DTC) on the Canada Revenue Agency (CRA) website is: “Has your impairment in physical or mental functions lasted, or is it expected to last, for a continuous period of at least 12 months?”

If an individual cannot answer “yes” to this question, they are considered ineligible for the DTC. The detail in the associated application form reveals the definition of “continuous” as 90 per cent of the time. This does not apply to many people with RRMS who can experience multiple periods of full, or almost full, recovery between relapses. Eligibility for the Canada Pension Plan Disability (CPP-D) Program is determined using an Adjudication Framework. Multiple sclerosis is specifically mentioned in this framework as one of the episodic conditions that may eventually allow the claimant to meet the criterion of having a “prolonged disability.” Although the CPP legislation does not specify a time frame, the policy reading of the clause included in the website states that an expected duration of disability of one year is a reasonable time frame to be eligible. Again, this excludes those with RRMS.

People with a disability are vulnerable to poverty, social exclusion, and dependence on social security. The Council of Canadians with Disabilities released a plan in 2010, which noted that large portions of working-age Canadians with a disability had low income. Further, the low-income rate was related to the severity of the disability (low-income rate of 31, 25, 18, and 14 per cent for those with very severe, severe, moderate, and mild disability, respectively). Ability to stay or return to employment is now being considered as an important outcome for

19 Furrie and Crawford, Towards a Better Understanding of the Dynamics of Disability.
20 Canada Revenue Agency, Are You Eligible for the Disability Tax Credit (DTC)?
21 Employment and Social Development Canada, Canada Pension Plan Adjudication Framework, 4.
22 Ibid.
24 Mendelson, Battle, Torjman, and Lightman, A Basic Income Plan for Canadians With Severe Disabilities.
individuals living with MS. Although a cure is not available for MS, there is a range of interventions or strategies available to help reduce the impact of the disease on QoL and employment.

**Interventions and Strategies for Individuals With MS**

Although the literature has identified many different interventions and strategies for individuals with MS, those summarized below are supported by the most compelling and recent evidence of effectiveness or are most frequently cited as being a promising intervention or strategy. In terms of therapeutic treatments, for which literature was most abundant, information that was provided in more recently published systematic reviews was included in the synthesis.

**Pharmacological Therapies**

Medications for MS can reduce the frequency and severity of relapses, as well as slow the progression of disability when taken early in the disease course, if it is a relapsing form.\(^{25}\) Unfortunately, there are currently no approved treatments for primary progressive MS. Health Canada has approved 11 disease-modifying therapies (DMTs) for people with relapsing forms of MS, and other emerging drugs may be added in the near future.\(^ {26}\) These drugs include Aubagio, Avonex, Betaseron, Copaxone, Extavia, Gilenya, Lemtrada, Plegridy, Rebif, Tecfidera, and Tysabri.\(^ {27}\) DMTs are designed to reduce the frequency and severity of clinical attacks or relapses/exacerbations. Some of these medications also reduce the accumulation of MRI-visible lesions within the brain and spinal cord while slowing the accumulation of disability in relapsing forms of the disease. While older DMTs have not been shown to improve the natural history of MS, current evidence suggests that earlier treatment with the newer DMTs does slow disease progression and the

\(^{25}\) Canadian Institute for Health Information, Canadian Multiple Sclerosis Monitoring System.

\(^{26}\) Multiple Sclerosis Society of Canada, Listening to People Affected by MS.

\(^{27}\) Multiple Sclerosis Society of Canada, Treatments.
accumulation of disability. This is important to note, as research that looked at the MS population in British Columbia suggests that rates of MS disease progression did not improve between 1975 and 2009. Therefore, there is a need for earlier and better treatment of MS that newer DMTs may provide.

Natalizumab has been shown to prevent clinical relapses, slow disease progression and MRI progression, and reduce disability. Fingolimod has also been found (via network and meta-analysis) to be effective in improving the same outcomes. Evidence also shows the effectiveness of alemtuzumab, glatiramer acetate, and interferon beta in reducing relapse rates and disease progression. Alemtuzumab, natalizumab, and fingolimod may even improve disability. The previously mentioned treatments will most likely no longer be compared with placebo in current and future trials, as new innovative drugs will be tested to go to market, and hence will become the new comparison. Although these drugs have been consistently shown to be effective in clinical trials and more recent systematic reviews

29 Zintzaras and others, “Network Analysis of Randomized Controlled Trials,” 857–69.
32 Pucci and others, “Natalizumab for Relapsing-Remitting Multiple Sclerosis,” CD007621.
33 Zintzaras and others, “Network Analysis of Randomized Controlled Trials.”
36 Zintzaras and others, “Network Analysis of Randomized Controlled Trials,” 857–69.
39 Zintzaras and others, “Network Analysis of Randomized Controlled Trials,” 857–69.
40 La Mantia and others, “Interferon Beta for Secondary Progressive Multiple Sclerosis,” CD005181.
42 Milo, “Effectiveness of Multiple Sclerosis Treatment,” 659–73.
referenced, these same studies also report long-term adverse effects, including infections and thyroid disorders in certain individuals.\textsuperscript{44} Dobson and others noted that due to these serious adverse effects, MRI could be used earlier to identify subgroups of patients for whom certain treatments would not be beneficial.\textsuperscript{46}

Provincial coverage for drugs needed by people with MS varies significantly across provinces, with some regions providing relatively restricted coverage.\textsuperscript{46} Further, access to the newest medications could be improved if Canada’s drug review process was streamlined, allowing drugs to be added to provincial/territorial drug formularies more quickly.\textsuperscript{47} This poses a significant challenge for individuals with MS in obtaining timely access to the treatment they need to best manage their disease and remain in or (re-)enter the workforce. This also poses further financial burden and inequities on those who do not respond well to the common MS drugs and who wish to access new therapies that have not yet been approved or added to the formulary. Aggressive and early intervention with newer therapies that aim to stop inflammation and reduce axonal damage has the best potential for improving long-term outcomes for individuals with MS.\textsuperscript{48}

There is some evidence to suggest that vitamin D may have an effect on disease progression, but this is still an active area of research.\textsuperscript{49} Weak evidence is available to support the use of prescription cannabinoids to relieve symptoms of MS, including pain and spasticity (muscle stiffness).\textsuperscript{50}

\begin{itemize}
\item \textsuperscript{44} Coles and others, “Alemtuzumab More Effective Than Interferon Beta-1a,” 1069–78.
\item \textsuperscript{45} Dobson and others, “Assessing Treatment Response to Interferon-Beta,” 248–54.
\item \textsuperscript{46} Multiple Sclerosis Society of Canada, \textit{Equitable Choice}.
\item \textsuperscript{47} Ibid.
\item \textsuperscript{48} Fox and Rhoades, “New Treatments and Treatment Goals,” S11–19.
\item \textsuperscript{49} Simon and others, “Vitamin D and Multiple Sclerosis,” 246–51.
\item \textsuperscript{50} Yadav and others, “Summary of Evidence-Based Guideline,” 1083–92.
\end{itemize}
Non-Drug Therapies
The many other types of available MS therapies are predominately used to treat symptoms that affect QoL and disability. These avoid the often serious side effects of drug-based treatments, and more research in these areas would lead to a better understanding of their potential. Based on the current literature, the following non-drug therapies are thought to be effective in reducing certain symptoms.

Occupational Therapy
Two reviews of occupational therapy alone,51 or as part of a multidisciplinary approach52 to manage MS symptoms, have concluded that there are some positive results from these approaches. The former noted that the two smaller studies in its review found a reduction in fatigue, though this was not seen in the higher-quality randomized controlled trial (RCT) the review included. The latter review considered occupational therapy as part of a wider group of rehabilitation interventions. It found that all three studies it included noted improvements in impairment or disability in people living with MS who had experienced relapse. This review urged caution in interpretation of its findings because of the small number of studies and their methodological limitations. Similarly, a meta-analysis looking at fatigue management in people living with MS found that rehabilitation interventions appeared to have stronger positive effects than drugs.53 However, a single recent RCT—not included in these reviews and analyses—found no benefit of rehabilitation on fatigue levels.54 Clearly, more research is needed into the impact of occupational therapy for people living with MS in order to clarify the therapy’s potential.

51 Steultjens as cited in Payne, Wiffen, and Martin, “Interventions for Fatigue and Weight Loss in Adults.”
52 Asano, Raszewski, and Finlayson, “Rehabilitation Interventions for the Management of Multiple Sclerosis Relapse.”
53 Asano and Finlayson, “Meta-Analysis of Three Different Types of Fatigue Management Interventions.”
54 Rietberg and others, “Effects of Multidisciplinary Rehabilitation on Chronic Fatigue.”
Physical Therapy and Physical Activity

Physiotherapy or physical training has been found to have some level of effectiveness on a number of outcomes in individuals with multiple sclerosis. In a review by Paltamaa and others, physiotherapy was found to have a small effect on balance in people with mild to moderate disability. In terms of specific interventions, this review found that particular balance exercises, resistance and aerobic training, and physical therapy based on individualized problem-solving had some evidence of beneficial effects. Amatya and others also found some evidence for the benefit of physical activity on spasticity. Strength training has been reported to improve gait and motor function; exercise, to benefit mood and QoL; and rehabilitation exercises, to improve bladder dysfunction.

Individuals with MS can also engage in certain levels of physical activity on their own. Physical activity involves movement of the body that is produced by contractions of skeletal muscles, increasing energy expenditure. Examples include leisure-time physical activity, exercise, sport, occupational work, as well as household chores and active transport for errands. A study by Motl and others found that physical activity among individuals with MS was associated with improvements in QoL. QoL was improved through decreases in depression, fatigue, and pain, and increases in social support and self-efficacy to manage MS. These can be considered as intermediate factors in the relationship between physical activity and QoL.

56 Amatya and others, “Non-Pharmacological Interventions,” CD009974.
57 Ibid.
58 Bounajm, Dinh, and Thériault, Moving Ahead.
59 Motl and others, “Physical Activity and Quality of Life in Multiple Sclerosis,” 111–24.
The Canadian Society for Exercise Physiology has produced guidelines for adults with MS. The guidelines recommend that those with mild to moderate disability should take at least 30 minutes of moderate intensity aerobic exercise twice a week and strength training exercises for major muscle groups twice a week.60

**Neuropsychological Rehabilitation**

Neuropsychological rehabilitation is described as encompassing therapeutic approaches concerned with the improvement of cognitive, emotional, psychosocial, and behaviour issues caused by damage to the brain.61 It involves teaching compensation strategies and using aids by patients and caregivers in order to better cope with impairment.

According to the Cochrane review by Rosi-Otajarvi and Hamalainen of 20 studies, neuropsychological rehabilitation was found to potentially improve a number of outcomes. (In the following sentence, the figure in brackets shows the standardized mean difference between control and treatment groups across all studies included in the review analyses.) Cognitive training on its own was found to improve memory span (0.54) and working memory (0.33), while cognitive training combined with other neuropsychological methods was also found to improve attention (0.15), immediate verbal memory (0.31), and delayed memory (0.22).

Also reported was the lack of impact on emotional functions—including depression, anxiety, and QoL—when results from the reviewed studies were pooled. However, the review does note that 18 of the 20 studies showed positive effects when evaluated individually.62 In contrast, a recent randomized trial study of 102 individuals with RRMS found that strategy-oriented neuropsychological rehabilitation reduced perceived cognitive deficits in MS rather than cognitive performance itself. This was found by looking at the perceived deficits questionnaire scores of the

60 Canadian Society for Exercise Physiology, *Canadian Physical Activity Guidelines*.
61 Wilson, “Neuropsychological Rehabilitation,” 141–162.
62 Rosti-Otajarvi and Hamalainen, “Neuropsychological Rehabilitation for Multiple Sclerosis,” CD009131.
control (score of 27.9) and intervention groups (score of 36.8) at the end of the study period. The estimated effect size was small, however ($\eta^2 = 0.077$).

### Mindfulness-Based Interventions

Mindfulness-based interventions are meditative techniques practised in groups or individually. They are meant to deal with comorbidity of MS and mental health issues that can affect treatment adherence, somatic symptoms, impairment of functional ability, and social status. A recent review looked at studies of mindfulness-based interventions for individuals living with MS. In the three studies included, mindfulness-based interventions were sometimes found to reduce anxiety, depression, and fatigue, and to improve QoL. The largest of the three studies (n = 150) more consistently found positive treatment effects than the two smaller studies (n = 16; n = 17).

### Mental Health Support Programs

The prevalence of psychiatric disorders is often far greater for individuals living with MS than in the general population. A recent study by Marrie and others estimated from administrative data that mental comorbidities in MS were statistically higher than the general population for several conditions: depression (32 per cent versus 21 per cent); anxiety (36 per cent versus 30 per cent); and bipolar disorder (6 per cent versus 3 per cent). Such comorbidity is associated with lower QoL, fatigue, and

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63 Mäntynen and others, “Neuropsychological Rehabilitation Does Not Improve Cognitive Performance.”

64 Simpson and others, “Mindfulness Based Interventions in Multiple Sclerosis,” 15.

65 Chwastiak and Ehde, “Psychiatric Issues in Multiple Sclerosis.”

66 Marrie, Fisk, and others, “Mental Comorbidity and Multiple Sclerosis,” 16.
Poor mental health in caregivers can lead to them being less effective in their caregiving.

reduced adherence to treatment in people living with MS.\textsuperscript{67} In one study, depression was also found to be higher in people living with MS who had retired early than it was in those who were still working.\textsuperscript{68}

Although there are no current statistics on the proportion of the Canadian workforce who provide informal care for individuals with MS, it has been estimated that 35 per cent of the Canadian workforce provide informal care, in general, to a family member or friend.\textsuperscript{69} Informal caregivers of people living with MS (often the spouse) also show increased rates of psychological illness, including depression and anxiety.\textsuperscript{70} In 2012, about 76 per cent of the workforce who provided informal caregiving to their spouse reported psychological distress and negative health consequences.\textsuperscript{71} Poor mental health in caregivers can lead to them being less effective in their caregiving\textsuperscript{72} or even increase the probability of potentially harmful behaviour.\textsuperscript{73}

For those with MS, a recent study found positive effects of peer support programs in terms of reduced depression, anxiety, and stress.\textsuperscript{74} The authors note that their findings were in contrast to an earlier study that found that peer support groups had no effect. They speculate that the difference between the studies may derive from the fact that many of the participants in the more recent trial were already receiving antidepressant medication and/or counselling. This was thought to place participants in a position where they could gain benefit from a peer support group. For caregivers, a range of supports is sometimes offered.

\textsuperscript{67} Marrie, Fisk, Stadryk and others, “The Incidence and Prevalence of Psychiatric Disorders in Multiple Sclerosis.”

\textsuperscript{68} Krause and others, “Employment Status in Multiple Sclerosis.”

\textsuperscript{69} Employment and Social Development Canada, \textit{When Work and Caregiving Collide}.

\textsuperscript{70} Buchanan and Huang, “The Need for Mental Health Care Among Informal Caregivers.”

\textsuperscript{71} Turcotte, \textit{Family Caregiving: What Are the Consequences?} (In this study, indirect costs included informal care as well as productivity losses, accounting for almost 50 per cent of the total indirect cost.)

\textsuperscript{72} Ibid.

\textsuperscript{73} Ibid.

\textsuperscript{74} Ng, Amatya, and Khan, “Outcomes of a Peer Support Program in Multiple Sclerosis.”
These include respite care, telephone therapy, and stress reduction training. These supports may reduce the burden of care and reduce levels of stress.75

**Workplace Adaptation and Accommodation**

Physical environmental factors are one of several important determinants of employment for individuals with MS.76 Physical issues in the workplace could include challenges in accessing work (transportation) and mobility within workspaces.77 Also, climate (high temperature) in work rooms can aggravate fatigue and weakness.78 Individuals with MS who work in open spaces may experience difficulties in concentration, and a lack of easy access to toilets can increase the risk of incontinence.79

Work accommodations relate to adjustments to either the employees’ work demands or allowing for flexibility in terms of where they can work and their hours. As physical disability increases in individuals with MS, many physical tasks become too difficult or impossible to accomplish. Other work demands—such as multi-tasking, working long hours, working full-time, and experiencing high levels of stress—can be equally difficult.80 Work instability—including unemployment, absenteeism, and presenteeism—results when work demand does not match the employee’s work capacity.81

Understanding the symptoms and disabilities of employees will allow better planning and decision-making around appropriate workplace adaptations and work accommodations for individuals with MS. One of the more effective approaches to doing this is to involve occupational therapists, or other professionals who have expertise in work

75 Buchanan and Huang, “The Need for Mental Health Care Among Informal Caregivers.”
76 Sweetland and others, “A Systematic Review of Research in Vocational Rehabilitation.”
77 Ibid.
78 Ibid.
79 Ibid.
80 Ibid.
81 Ibid.
It is important for individuals with MS to discuss workplace needs as soon as possible.

rehabilitation or vocational rehabilitation, before symptoms become severe. Similar to greater effectiveness of earlier treatment, workplace interventions by way of adaptations and accommodations are more effective when they occur earlier in the course of the employee’s MS. It is, therefore, important for individuals with MS who wish to remain employed to discuss these workplace needs as soon as possible with their employer.82

The more recent literature on employment status and MS suggests that workplace adaptations and accommodations more frequently address mobility limitations and other “visible disabilities” as opposed to fatigue, pain, and cognitive problems, which are considered “invisible disabilities.”83 Progress in this area should address ways in which employers can adapt work environments to compensate for these potential cognitive deficiencies. Further, organizational responses to communication of an MS diagnosis should exhibit trust, offer inclusive decision-making, and focus on employees’ abilities instead of their disabilities. This can enhance employees’ perceptions of psychological safety in the workplace, thus increasing the likelihood of employment retention and reduced presenteeism.84

There are some resources for employers to help them better understand what work adaptations and accommodations are, and their implications for business. The MS Society of Canada has published an employer guide that provides simple information about MS, treatment, statistics, MS and employment, accommodation, and legislation around employee communication of an MS diagnosis.85 In addition, the Canadian Council on Rehabilitation and Work offers programs that can assist employers wishing to retain or employ workers with MS. For example, the Council’s Job Accommodation Service (JAS) is a fee-based program that provides education, advice, and assessments to employers seeking to make

82 Simmons and others, “Living With Multiple Sclerosis.”
83 Ibid.
85 Multiple Sclerosis Society of Canada, MS in the Workplace: An Employer’s Guide.
workplace accommodations. The Ready to Work Inclusion Program (RWIP) provides a six-month wage subsidy that is intended to support employers “… in training, accommodating, and retaining persons with disabilities.”

Eligibility criteria for the RWIP scheme specifically states that people with episodic barriers to employment (such as is often the case for individuals with MS) are considered. The JAS is a fee-for-service scheme, usually paid for by the employer, while the RWIP is subsidized by the federal government. The Government of Canada, through Employment and Social Development Canada/Service Canada, runs the Opportunities Fund for Persons With Disabilities Program. This gives financial assistance to organizations that help people with disabilities obtain or maintain employment. As employers anticipate a changing workforce demographic that includes more employees with chronic conditions, they will need more and better resources to help them understand this workforce. This will enable the employers to leverage their employees’ capabilities and support their development, while building a strong business.

While the processes and possibilities for workplace adaptation and accommodation may be more refined in large employers, there are many steps that small and medium enterprises (SMEs) can take. These are important as there are many potential benefits to SMEs of employing a person with a disability, as well as legislation that requires an employer to make accommodation where possible. Many workplace accommodations that can benefit people with MS are relatively inexpensive and the cost can sometimes be recovered.

86 Canadian Council on Rehabilitation and Work, *Job Accommodation Service*.
87 Canadian Council on Rehabilitation and Work, *Ready to Work Inclusion Program*.
88 The Conference Board of Canada, *Employers’ Toolkit*.
through government schemes. The updated Conference Board of Canada Employers’ Toolkit contains lists of tips for small businesses and resources related to employing people with disabilities.

Vocational Rehabilitation

As mentioned earlier, occupational therapists and other professionals play an important role in assessing work environments to help plan appropriate work adaptations and accommodations. This type of function fits under the larger umbrella of vocational rehabilitation. Vocational rehabilitation is described as the provision of vocational or work assessment, rehabilitation services, and other supports. These aim to enable individuals with MS to remain in, regain, or find satisfying employment, as well as to better access other job-related and educational opportunities.

It has been suggested that vocational rehabilitation services are best provided by a multidisciplinary team that may operate both within the health system and the community. The team can provide education on active communication of diagnosis, supply information on workplace accommodation and adaption, offer emotional support, maintain work performance, liaise with employers, and support individuals with MS to remain in and re-enter the workforce. In addition to occupational therapists, this multidisciplinary team could include physiotherapists, neuropsychologists, physicians, and nurses.

Vocational rehabilitation services covered by provincial health plans are accessed through referral by a physician to one of the medical professionals listed above. Individuals requiring these services sometimes access them privately. Also, some extended health care benefit insurance packages cover services that could be deemed as having a vocational rehabilitation function. The vocational rehabilitation

89 Multiple Sclerosis Society of Canada, *MS in the Workplace: An Employer’s Guide.*
90 The Conference Board of Canada, *Employers’ Toolkit.*
91 Doogan and Playford, “Supporting Work for People With Multiple Sclerosis.”
92 Ibid.
program currently offered by Service Canada is entirely focused on return to work, rather than job maintenance. Indeed, participation in the program is dependent on receipt of the CPP-D benefit. This requirement effectively bars those already working but who require assistance to stay at their job. Currently, in order to receive assistance, those working individuals would need to leave their job, apply for and receive the CPP-D benefit, submit an application for the vocational program, and then find a job again. If access to the program was not linked to the CPP-D benefit, an individual could access services without the need to leave work, which would benefit all parties more than the current system. Services in this program are limited to those resembling employment services, in that assistance is offered in identifying job skills, goals, and employment search strategies.

Active Communication of Diagnosis

Often individuals with MS are concerned with actively making their illness known to their employer because they fear discrimination and termination of employment. Both the Multiple Sclerosis Society of Canada and the U.S. National MS Society provide advice for individuals on the pros and cons of telling an employer about their MS. Pros include the stress of keeping MS a secret, potential support and accommodation, preempting possible future problems, and negative consequences if job performance deteriorates with no apparent reason. Cons include the inability to take back the information, exposure to negative reactions, denial of promotion, and not receiving accommodations. The MS Society of Canada has also produced a document to help employers unfamiliar with MS, *MS in the Workplace: An Employer’s Guide*. The society suggests employees having a discussion with their employer could use this to inform the conversation. This may be especially true in the case of a small organization/employer that may not have previously

93 Service Canada, *Vocational Rehabilitation Program*.


95 Multiple Sclerosis Society of Canada, *MS in the Workplace: An Employer’s Guide*.
Employees who had actively communicated their diagnosis were more likely to be employed.

Employees who had actively communicated their diagnosis were more likely to be employed. Legally, employees are not required to actively communicate diagnosis. When an employee requires workplace adaptations or accommodations, he/she is required to discuss only those symptoms or specific needs that allow him/her to remain in the workplace.96

Very recently, more research around the communication of diagnosis of MS in the workplace has been produced. Two studies have been published about making an MS diagnosis known to employers, and its impact on employment status, job tenure, and accommodations. The first study surveyed a large sample of 673 employed individuals with MS in Australia in 2012.97 This study had two objectives: 1) to observe the relationship between communication of diagnosis to employers and employment status over a three-year period; and 2) to observe the relationship between this communication and perceptions of positive or negative employer attitudes toward MS. The research found that employees who had actively communicated their diagnosis were more likely to be employed, and for longer periods of time, even after controlling for the severity of their disability in the analysis. In addition, it was found that the majority of employer responses (as perceived by the employees) to an employee disclosing an MS diagnosis were positive and supportive.

These findings were supported by another study published by Frndak and others just a few months after the first study.98 This work additionally commented that accommodations for cognitive dysfunctions were less likely than accommodations for more physical or mobility limitations. Both studies supported the theory that the existence or increase of work

96 Multiple Sclerosis Society of Canada, Talking About MS/Employers; National MS Society, Disclosure Decisions.


98 Frndak and others, “Disclosure of Disease Status Among Employed Multiple Sclerosis Patients.”
problems related to MS increases the likelihood of active communication of MS diagnosis, which then increases the likelihood and number of accommodations.

The results of both studies seem to suggest that active communication, although a risky strategy for individuals, is likely to be a positive strategy in remaining employed for longer periods of time. More research would be required to further understand the impact of active communication on employment under different contexts. For example, it was found that the increased likelihood of communicating MS diagnosis was associated with having worked longer for an employer.\textsuperscript{99} However, it is not clear if the period of employment is also linked to the likelihood of a positive employer response. The best test of this situation would be the response to communication of an MS diagnosis during the job application or interview process. Other potentially important contextual aspects are the organization’s size and the amount of experience it has in responding to an employee communicating an MS diagnosis.

**Employee Benefits**

The MS Society of Canada has produced a guide to employment and income for individuals with MS. The guide includes information regarding income benefits and employment programs for those who are leaving work and who are returning to work.\textsuperscript{100} The document discusses questions that employees should ask at some point after their diagnosis, including:

- which sick leave, short-term, and long-term disability insurance their employer provides;
- whether there is a collective agreement or plan that allows partial disability and/or part-time employment;
- what other health benefits are provided, including how to access these benefits;

\textsuperscript{99} Ibid.

\textsuperscript{100} Multiple Sclerosis Society of Canada, *A Guide to Employment and Income Support*. 

Find Conference Board research at www.e-library.ca.
• whether benefits cover necessary drugs, disease-modifying therapies, extended health benefits, complementary and alternative medicines, hospital insurance, and home and community care.

When, or if, an employee asks these questions and attempts to access benefits is largely a matter of personal choice. However, as previously discussed, some evidence suggests that it can be more beneficial if questions are brought forward earlier in the disease course.

An example of insurance that provides coverage for MS is critical illness insurance schemes. Critical illness insurance typically provides a payment upon diagnosis of a critical illness by a specialist. Critical illness insurance provided by Sun Life, Great-West Life, BMO, and Canada Life, for example, provide full payout for MS. Although the majority of employers do not cover critical illness insurance as part of their employer-sponsored benefit plans, some offer employees the choice to purchase this insurance. The issue here is that many employees often opt not to pay for this critical illness insurance, as they often do not see the risk of developing such conditions over their employment tenure.

In addition to this issue, it has been noted that some people who are in receipt of long-term disability (LTD) benefits through their employer or an insurance company are subject to policy provisions in their plan, which takes benefits received from other sources into consideration. For example, benefits received from CPP-D may be offset (i.e., subtracted) from the monthly LTD benefit amount. In some cases, this may result in a loss to the recipient because CPP-D is taxable income, whereas some LTD plans are not. The net effect of this situation on an individual’s income will, of course, depend on their overall taxable income. Another complication is that CPP-D qualifying criteria state that contributions

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102 Offsetting is often negatively referred to as a “clawback.”
The possibility of reduced income is a disincentive that is important to note.

must be made in four of the previous six years in order to be eligible. This adds pressure on those individuals who anticipate being on LTD for more than two years to apply for CPP-D.

The possibility of reduced income is a disincentive that is important to note because receiving benefits that may reduce private LTD payments can have advantages for claimants as well as private insurers. (Receiving CPP-D, for example, can help maximize future CPP retirement benefits.) However, the risk that net income can be reduced and the mere possibility that claimants could receive a bill for unpaid tax, along with the uncertainty and complication of going through the application process, counter the advantages to undertaking it.

A clear view of the processes involved in applying for LTD, CPP-D, and other benefits, and the consequences of applying (or not) for each, should be easily accessible to those who need the benefits. The complex interplay between public and private benefit plans needs to be understood by an individual who is in the course of considering work arrangements in light of their MS symptoms. This understanding and the subsequent actions an individual takes could influence decisions on their future work plans. People considering these decisions are already in a stressful position and need to make many critical choices at a time when disease symptoms may make dealing with such situations more difficult. For this reason, it is all the more important that the stakeholders involved—including employers, insurance providers, and government—collaborate to make the processes, choices, and consequences of benefits applied for, as clear and transparent as possible.

Family caregivers who are employed are eligible for compassionate care benefits under federal and provincial employment standards. However, these are aimed at people who need to be away from work temporarily to care for a critically ill family member who has a significant risk of death within 26 weeks. These benefits usually cover a maximum of 8 weeks during the 26-week period. This is not usually the situation for those caring for a family member experiencing an episode of worsened symptoms.

103 Meredith and Chia, Leaving Some Behind.
MS symptoms, as is characteristic in RRMS. Leave provisions within employment standards that may be used in this situation are less common.104 Many employers have their own formal policies in addition to those required by employment standards that provide care and/or sick leave.105 In addition, tax credits for caregivers are available from all provinces as well as the federal government.106 For many caregivers, eligibility for the allowance can be considered restrictive—especially when they are taking care of someone with an episodic condition.

Employment Insurance (EI) sickness benefits programs exist for individuals who are ill and therefore unable to work. However, these programs often do not consider the context for an individual living with a chronic, episodic disability, such as is often the case with MS. These programs support a traditional perception that disability is a continuous state rather than one that can change over time and be virtually absent for long periods.107 Many individuals with MS have the capacity to work intermittently due to the episodic nature of their disease. There have been calls to the federal government to convene a national policy dialogue to explore making EI sickness benefits more flexible. The objective is to allow individuals with episodic disabilities to work part-time and/or intermittently while receiving partial benefits for up to 150 half-days as needed, as opposed to the current requirement of 15 consecutive weeks or 75 full days of sickness.108

Employers and governments could support employment for individuals with MS through the provision of flexible employment insurance and employee benefits. These provisions can reduce the need for full disability benefits for some, and increase GDP through contributions to income taxes, employment insurance, the Canada Pension Plan, and other contributions. As well, this type of support also contributes skills

104 Ibid.
105 Thorpe and Chénier, Disability Management: Opportunities for Employer Action.
106 Verbeeten, Astles, and Prada, Understanding Health and Social Services for Seniors in Canada.
107 Furrie and Crawford, Towards a Better Understanding of the Dynamics of Disability.
to the labour force and boosts productivity\(^{109}\) (See “The Cost of MS to Employers.”) For an extended discussion of how workers and their families are supported in Canada during a period of illness or disease, including episodic disease such as MS, see the recent report by Meredith and Chia.\(^{110}\)

### The Cost of MS to Employers and the Benefits of Adequate Drug Coverage

The cost due to productivity loss has been estimated to account for 33 to 47 per cent of the overall cost of MS.\(^{111,112}\) Aside from the clinical benefits associated with successful interventions for RRMS, some studies have shown that at least part of the lost productivity due to MS can be regained as well. This type of analysis is important as it allows employees, employers, and policy-makers to see the monetary benefits, as well as the costs, of intervention. These can then be weighed into decisions regarding covering drugs or other DMTs in formularies and insurance policies prescribing and adhering to a DMT regimen. The current literature in this area is mostly limited to studies looking at the benefits of new pharmacological interventions. (See the next paragraph.) The addition of work-related benefit measures to future research would provide a fuller cost-benefit picture and may encourage intervention development and adoption by including these wider benefits. (See Appendix B for a brief synopsis of forthcoming Conference Board work in this area.)

Intervention benefits related to productivity included more working hours, greater ability to cope with work requirements, greater disease stability, and reduced sick leave.\(^{113,114,115}\) These effects were all found in studies looking at the use

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109 Ibid.
110 Meredith and Chia, *Leaving Some Behind*.
111 Oleen-Burkey and others, “Burden of a Multiple Sclerosis Relapse,” 57–69.
113 Ibid.
115 Wickstrom and others, “Reduced Sick Leave in Multiple Sclerosis,” 1095–1101.
of natalizumab. One of these noted that the estimated value of the increases seen in productivity (~4000 Euros year-1) offset around 36 per cent of the extra cost of natalizumab over other DMTs.\textsuperscript{116} It also points out, though, that this is not a true reflection of the incremental benefit of natalizumab because possible productivity gains from the other DMTs are not accounted for. A recent review of the benefits of DMTs, in general, found that they likely have a favourable effect on employment and work productivity, although it notes that data on natalizumab and finogolimod are deficient.\textsuperscript{117}

### Health Care System

Rehabilitation services—such as occupational therapy, physiotherapy, speech and language therapy, neuropsychology, and other specialized services—are often not all covered within the health care system. Similar to drug coverage, health services coverage is heterogeneously covered across provinces and territories. There is a need to create better access to and better care coordination across the traditional and universally covered health care system (physician and nursing care) and the frequently fragmented rehabilitation services sector. The complexity of MS requires a full range of services to help individuals living with MS.

The first issue many people face when trying to access health care is being knowledgeable about which services or resources are available, how to access them, where to look, and how to request access. Due to the many points of contact these individuals will have within the system, it is important that they are able to efficiently and effectively navigate the system. This can be a challenge for any Canadian, and even more so for someone suffering from the common symptoms of MS—such as impaired speech, vision, and cognitive functioning. Even when these challenges have been overcome, there may be wait times to access some specialists or specialized services such as rehabilitation

\textsuperscript{116} Olofsson and others, “Effect of Treatment With Natalizumab,” 299–306.

\textsuperscript{117} Owens and others, “Perspectives for Managed Care Organizations.”
services. These access issues can be further compounded if treatment is sought in a rural area. Finally, many institutional care facilities are populated by residents who are much older than the typical person with MS who is looking for residential care. This may lead to a mismatch between the services and programs offered and the needs of those individuals with MS seeking care in these settings.

Caregiver Burden and Support

Individuals with MS do not want to be a burden to their families and worry about how their condition/disease affects the QoL of their families. In the Listening to People Affected by MS report by the MS Society of Canada, it was noted that “... there is no structured support system in place specifically for caregivers, nationally or provincially.” This lack of assistance belies the enormous value of caregivers—especially informal caregivers—as both aids for people with a range of challenges (including MS) and as employees. (See “The Importance of Informal Caregivers in Canada.”)

In general, understanding the demands on, and the needs of, unpaid caregivers in Canada is not as prominent as it could be. Indeed, in a recent action plan, the Canadian Caregiver Coalition includes enhanced awareness of caregiver needs and the creation of supportive workplaces as two of their four key areas of focus. Specifically, the plan states that employers should recognize caregivers within their human resource strategies, and that the federal government should support consultation on tax incentives for employers by 2016. Both of these proposals could

118 Based on the general observation that wait times are longer for the patient group identified as “neurological conditions” than for other patient groups. In 2012, it was estimated that patients with neurological conditions waited, on average, eight days for admission for rehabilitation services and about two days for discharge. This group of conditions ranked third worst out of 16 patient groups in terms of wait times for rehabilitation. See Canadian Institute for Health Information, Health Care in Canada 2012: A Focus on Wait Times.

119 Multiple Sclerosis Society of Canada, Continuum of Care.

120 Multiple Sclerosis Society of Canada, Access to Appropriate Residential Care.

be relevant to unpaid caregivers of people with MS if employers and
the government recognized the particular issues associated with the
disease—such as its often episodic and unpredictable nature.

The Importance of Informal Caregivers in Canada

• In 2012, the General Social Survey (GSS) found that 8.1 million Canadians reported they had provided informal care within the last 12 months.
• Of these, 6.1 million were in the workforce (this equates to 35 per cent of working Canadians).
• Furthermore, over 5 per cent of those who provided care reported that it was for people with neurological diseases.
• The 2012 GSS also reported the number of caregivers who:
  – took leave from work = 1.6 million
  – reduced their work hours = 600,000
  – turned down paid employment = 160,000
  – resigned their job to provide care = 390,000.
• Estimated reduced work effort by caregivers in 2012 = 2.2 million hours.
• Estimated loss of full-time employee equivalents in 2012 = 157,000.
• Estimated cost to Canadian firms in lost productivity per year = $1.3 billion.

Sources: Sinha, Portrait of Caregivers; The Conference Board of Canada.

There were few studies in our literature review that addressed the challenges that caregivers of individuals with MS face in relation to QoL and employment. However, one study did look at the self-reported need for mental health counselling among caregivers of individuals living with MS.122 Among other factors, this study found that the higher a caregiver scored on mental health-related QoL questions, the lower the likelihood of requiring mental health counselling (although the regression coefficient for the factor was small—0.075). Another study looking at the same data examined which aspects of caregiving for a person with MS

122 Buchanan and Huang, “The Need for Mental Health Care Among Informal Caregivers.”
predicted reduced employment.\textsuperscript{123} This study found that inferior cognitive ability of the care recipient, more caregiving hours, and worse physical health were all significantly associated with reduced employment.\textsuperscript{124} The association between caregiver mental health and perceived need for counselling is congruent with the results of a study that looked at caregivers, overall, in Canada.\textsuperscript{125}

The study reported that among those who spent at least two hours per week providing care, 21 to 38 per cent reported feeling depressed, depending on for whom they were caring. These findings are also largely in concert with a recent review of literature on the impact of informal caregiving on employment, health, and family, in developed countries.\textsuperscript{126} The review's authors concluded that caregiving has a negative impact on the caregiver's psychological health (and through this, their physical health) and employment. However, in contrast to the estimates above, the findings also showed that the impact on caregiver employment is small, with caregivers at most only 5 to 10 per cent less likely to be employed than non-caregivers. Similarly, the results concluded that although there is consistent evidence that caregivers work fewer hours, the effect is again relatively small. Crucially, however, the study does note that there are regional differences in the findings and that these may be related to the level of support for caregivers in the form of financial benefits, entitlements to leave, or flexibility of working arrangements.

This final point is particularly important when one considers that, in Canada, one of the greatest challenges faced by caregivers is the inability to find the supports, financial or otherwise, they need for

\textsuperscript{123} Buchanan, Huang, and Zheng, “Factors Affecting Employment Among Informal Caregivers.”

\textsuperscript{124} The regression coefficients, 0.586, 0.396, and 0.098, respectively, reveal that cognitive ability and number of hours are relatively more important.

\textsuperscript{125} Turcotte, Family Caregiving: What Are the Consequences? In this study, indirect costs included informal care as well as productivity losses, accounting for almost 50 per cent of the total indirect cost.

\textsuperscript{126} Bauer and Sousa-Poza, “Impacts of Informal Caregiving on Caregiver Employment, Health, and Family.”
themselves or to assist them in caring for their loved ones. Resources such as respite care services are often limited and caregivers find themselves frequently on waiting lists. Caregivers also experience health care and social services system navigation issues. With a lack of assistance, caregivers’ ability to take care of themselves and participate fully in the workforce is impeded.

The federal government recently released the Canadian Employers for Caregivers Plan, which acts as a guide to how employers can support their caregiving employees. The plan led to the creation of the Employer Panel for Caregivers in 2014 by the Minister of State for Seniors. The Employer Panel’s mandate is 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.) 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. In terms of barriers to providing support, the consultations by the Panel with employers found that lack of awareness, the nature of the job, and leadership support were existing challenges. One of the key take-away messages was that employers still wanted to understand the business case for supporting employee caregivers in the workplace, despite knowing that it was “the right thing to do.” In addition, employers preferred user-friendly and broad policies that could be adapted to their own needs, instead of restrictive, one-size-fits-all legislation.

It is encouraging to see steps taken at the federal level to understand and provide employers with tools to support employees who are caregivers. However, we are still a long way from creating a robust system within and outside of workplaces to help caregivers not only

127 Multiple Sclerosis Society of Canada, *Listening to People Affected by MS*.
support their loved ones, but also to help themselves financially, socially, and health-wise. Previous Conference Board research has found that tax credits for eligible caregivers can be accessed in all provinces, as well as from the federal government.\textsuperscript{129} Also, as mentioned previously, compassionate care leave is now available in all provinces, and compassionate care benefits for up to six weeks are available for those who are eligible. (However, utilization of this leave was reported to be extremely low in the past.)\textsuperscript{130} The extent to which those who give care to individuals with MS can access these benefits is unclear, given that definitions of “disability” and “infirmity” sometimes exclude those with episodic diseases such as MS. All provinces also offer respite services, though the extent to which these can be accessed is sometimes limited because of administrative inconvenience and scheduling.

Beyond these widely offered services and programs, there exist a couple of notable supports and innovations within individual provinces. For example, Manitoba is the only province in Canada with caregiver-specific legislation (Caregiver Recognition Act, 2011) and only Nova Scotia offers direct grants to caregivers (however, the monthly allowance of $400 is accessed by only about 1,700 people). At the international level, the U.K., Denmark, and, to a limited extent, Sweden, provide some level of caregiver allowance. In addition, local councils in the U.K. are required to give an assessment of the help a caregiver requires, either directly to them as a caregiver or to the person for whom they are caring. The result of this assessment can lead to a range of assistance, including help with such things as travel costs, the purchase of a computer, driving lessons, and massage and/or leisure classes for stress reduction.

\textsuperscript{129} Verbeeten, Astles, and Prada, \textit{Understanding Health and Social Services for Seniors in Canada}.

\textsuperscript{130} Keefe, \textit{Supporting Caregivers and Caregiving in an Aging Canada}. 
CHAPTER 3

Insights From a Stakeholder Workshop

Chapter Summary

- Leadership and funding are required to implement changes that will positively affect workforce participation by those living with multiple sclerosis.

- The complex array of employer, insurance, government, and health system options available to persons with MS, and to their caregivers, needs to be better aligned and easier to navigate.

- More employer and public awareness of the issues people living with MS face would benefit all parties. This is especially true of the “invisible” side of MS.
Stakeholder Workshop Methodology

A facilitated, full-day, face-to-face workshop—including a group of 24 stakeholders—was held on November 16, 2015, in Toronto, Ontario. Participants represented a range of stakeholder groups, including federal and provincial/territorial governments, not-for-profit organizations, employers, insurers, researchers, individuals with MS, and caregivers.

The main objectives of this workshop were to validate, respond to, and expand on the issues raised in the discussion guide (the literature review component of this report). In addition, the workshop provided the opportunity to achieve consensus on key issues, including the identification of potential solutions to better support Individuals living with MS, and the caregivers of these individuals, from an employment perspective.

At the start of the workshop, participants were introduced to the project and provided information on the overall goals and objectives of the research and workshop. The participants were given three questions that were to be addressed throughout the day in smaller groups. The questions are as follows:

- What did you notice/stand out for you in the Conference Board’s *Multiple Sclerosis in the Workplace* discussion guide (literature review)?
- What do you think are further opportunities for improving successful employment of individuals with MS and their caregivers?
- What do you think are the challenges or barriers to achieving necessary changes?
- What are your top three recommendations for improving employment experiences and opportunities for individuals with MS and their caregivers?
Comments regarding the discussion guide are integrated or addressed in Chapter 3 of this report. The insights from the workshop discussions are summarized in this chapter with highlights of the key points that arose throughout the day.

One of the limitations of this workshop was the lack of representation from employers representing small to medium enterprises (SMEs). Although several organizations were approached to represent the SMEs, the Conference Board was unable to secure participation from a representative of this stakeholder group. In general, however, the discussion captured a range of issues and potential solutions from a variety of stakeholders, including the potential challenges faced by SME employers.

**Challenges to Change**

The barriers and challenges, which participants at the workshop associated with some of the specific actions discussed, are listed in this section. However, aside from points related to specific actions, it was felt that there are two main challenges relevant to all of the recommendations:

- First, who should be the champion for these ideas?
- Second, what is the source of funding for these ideas?

How these questions would be answered is important to keep in mind when considering the specific challenges and barriers below:

**Resources and System Navigation**

- The MS specialty clinics located in 22 major cities across Canada can provide practical and emotional support. The MS Society of Canada also has divisions in every province and territory to offer support. However, not all persons with MS and their families have easy access to these supports, particularly those people located in rural communities. In addition, not everyone is referred to the MS specialty clinics. All persons with MS and their families need to know about the existence
of the national network of MS clinics in Canada, the MS Society, and the services these organizations provide. This report provides the first step in letting people know.

• The clinics and MS Society are very busy caring for the needs of individuals with MS and their families. Often, the clinics and the MS Society do not have the personnel who are trained and knowledgeable in regard to employment issues, and how to navigate the complex system of insurance company and government benefits. There is a great need for social workers and/or vocational rehabilitation specialists to become part of the MS care team. How this could best be accomplished within the current health care system and economic environment is a challenge that needs to be addressed. MS health care providers—including physicians, nurses, and rehabilitation therapists—are already under a large burden to provide excellent, up-to-date medical care. Having personnel to refer to about employment issues would make a significant positive impact on the care the clinics feel they are able to provide to their patients.

• Many physicians care for persons with MS outside of the MS specialty clinics. These physicians also need access to information and help in aiding their patients to navigate employment issues.

• The information that is available to people living with MS, their caregivers, and employers is very difficult to navigate. Often, health care providers and employers just don’t have the time required to understand all the complexities of the various plans and benefit programs. In addition, it can be difficult to find the information or to even know that there is information. Therefore, information is sometimes not even sought after. There needs to be awareness that the information is, indeed, available. Further, this information should be available in an easy accessible, understandable, and comprehensive format.

• Many people may not know they can ask for accommodation in the workplace.

• The government programs available to employers are not clear and/or it is not obvious that they exist.
• There is a need for better and current data in order to make productive decisions, including the necessity for more high-quality research regarding employment issues for people living with MS and for their caregivers.

• Information overload may make informing about the episodic nature and invisible symptoms of MS difficult, as there are many competing priorities in the public domain, such as the current focus on mental health in the workplace.

• There is a need to develop a way to share best practices across the country—province to province, employer to employer.

Financial Issues

• Small businesses may have challenges and issues with the affordability of benefit packages and providing workplace accommodations. Small business employers may want to help their employees, but do not have the same resources that larger companies have.

• Similarly, businesses and employers in rural communities may not have the same level of resources and services to help their employees as do businesses and employers in urban areas.

• Getting to work can be an issue for people living with MS, especially with regard to transportation if they require special accommodations to be made to their vehicle or need to rely on public transportation services for the disabled.

• Perhaps the ultimate challenge involved with all the initiatives suggested in this report, as already mentioned, is the financing to turn these initiatives into reality (e.g., a single point of reference for all information and resources and finding a group to champion them).

Employment

• The type of job can often be barrier to flexibility; for example, a production job versus an office job.
• Sometimes people with MS or their caregivers can’t advance in their career as much as they would like because they are dependent on current employers’ benefit packages.
• There may be a fear of retraining, trying a new position, and sharing one’s diagnosis with the employer.
• Small business employers may have more challenges in providing flexible, supportive options to help their employees retain employment.

**Government and Insurance Plans**

• The regulatory policies and legislation at all levels of government and with the insurance industry are not efficient in the way they work and are delivered. For example, employment insurance, CPP-D, and insurance benefits are confusing and often generate a sense they are not working together for the person living with MS.

• Some people living with MS, or their caregivers, could work part-time. But the impact on benefits is often perceived as drastic and confusing, which creates additional anxiety.

• Currently, many benefit plans do not support the episodic illnesses, such as MS. Rather, they support a more all-or-none working distinction. This may then result in a disincentive for people with MS, or their caregivers, to try and continue working in some fashion.

• People with MS, or their caregivers, may want to pursue employment of some type, but are not sure how to begin looking. As well, they are unsure of the impact their diagnosis will have on their eligibility for benefits.

• Canada is a large and diverse country with many levels of government, numerous policies, and several insurance companies. Thus, it is difficult to know how to best develop consistent, practical ways to assist with better insurance packages, incentives for employers, and comprehensive workplace accommodation.
Top Three Recommendations

Workshop breakout groups were asked to identify their top three recommendations for action in order to improve employment experiences for individuals living with MS and for their caregivers. The following are three recommendations that were identified based on a consensus of ideas from the entire group.

1. Establish Supports to Help Individuals and Caregivers Navigate the System and Their Choices

At the time of diagnosis, people with MS and their families have a tremendous amount of information to process and assimilate. Employment issues are one of the major concerns of persons when they are first diagnosed. People often wonder: Can I keep working? Can I still do my job? Will I have to go on disability? Will I have to retire early? How can I continue to support my family? These are difficult questions that do not have any easy answers.

Similarly, caregivers wonder if they’ll be able to keep working, or if they’ll have to stay home to take care of their loved ones. Or, perhaps they may wonder if they will need to look for work and become the main providers. Because there are so many issues to consider upon diagnosis, a single health care provider is not able to cover every issue. Multidisciplinary MS care teams are needed to help people with MS and their families address all the issues, including employment. For example, social workers and/or vocational rehabilitation specialists could help with employment issues, allowing the neurologists, nurses, and rehabilitation therapists to focus on the medical aspects of the diagnosis. Social workers and/or vocational rehabilitation specialists need to become an integral part of the MS care teams across the country.

Support, in particular, needs to focus on retention of employment—perhaps not the same job in the same place, but the ability to work in some capacity. This support may need to come in the form of retraining. For example, a person with MS who had been working as a lab technician recognized that her ability to remain on her feet for
an eight-hour shift would not be possible as her balance deteriorated. She chose to retrain in the area of finance so she could still work, but in a job that required her to sit rather than stand. This type of support focuses on what the person with MS can do, and helps him/her think through potential options for work. These options include part-time work, working from home, changing jobs, or re-training. They need to occur early on in the disease process so plans can be made before a crisis or other circumstances force a change to be made regarding employment. The same is true of caregivers. The earlier the person with MS, and his or her caregiver, can think through potential solutions for employment before a change becomes absolutely necessary, the less stressful the transition will be.

Support also needs to come in the form of a national single point of contact for information on employment resources and options. The amount of information regarding disability benefits, retirement packages, sick leave options, etc., is difficult to sort through to determine what may be the best option for a particular person and/or caregiver at this particular time. This is difficult not only for persons living with MS and their families, but for MS health care providers as well. A single point of contact would greatly alleviate the confusion and stress involved in researching all the available options. This single point of contact should be made available to individuals living with MS, caregivers, employers, and MS health care providers. It should consolidate all available information on employment issues and options from government, insurance companies, and advocacy agencies, such as the MS Society of Canada.

2. Enhance the Role of Employers, Insurance Companies, and Government

Government and insurance companies should develop an employer support program that includes education about the nature of the disease of MS—in particular, how in the beginning stages, the majority of those diagnosed go through periods of relapses and remissions. In times of relapse, people most likely will have difficulty working, if they can work
at all. Whereas, in times of remission, they may well be able to do their job fully, or perhaps with some minor modifications. This episodic nature of MS presents a unique situation for employers, insurance companies, and government. Employees may need access to several short-term sick leave or disability benefits to recover from their MS relapse, but then be able to return to work. In some cases, the employee with MS may be able to return to work as per usual before the relapse. However, relapses do take their toll, especially after particularly severe episodes and/or repeated episodes. Employers, insurance companies, and government may also have to consider modifications that would continue to allow the person with MS to work. The modifications might include working fewer hours, functioning in a different capacity, job-sharing, or even moving the employee’s office next to the bathroom. Perhaps, looking at how employment can be retained for persons with MS (given its episodic nature) could pave the way for understanding how employment issues could best be handled in other episodic diseases.

In addition, employers should be made aware of the invisible side of MS. Often the first impression people have when they see the letters “MS” is that the afflicted person can’t walk. While it is true that people with MS can have difficulty walking, this is only one aspect of the disease. One of the most troublesome symptoms of MS is fatigue. Many people living with MS often say fatigue is more difficult to manage than the arduous walking. Other troublesome symptoms include pain, bladder/bowel issues, depression, and cognitive dysfunction. All of these invisible symptoms can affect how a person with MS is able to fulfill his/her job roles and responsibilities. Insurance companies and governments need to be made aware of these invisible symptoms and their impact on the ability to work. They can then incorporate this information into their information and option packages for employers. A much greater emphasis needs to be placed on these invisible symptoms than has been traditionally done to date.
The treatments for MS often come with side effects; some are quite severe. This also needs to come to the attention of employers and the general public, as side effects can also have a profound impact on the person’s ability to fulfill his or her roles and responsibilities as previously done.

There is an opportunity for a more proactive approach on behalf of employers, insurance companies, and governments. This approach can help reduce the cost, misinformation, and ad hoc approach that often ensues when trying to deal with the employment issues of people with MS and their caregivers. A review of all programs provincially and nationally to develop a cohesive and consistent approach to employment issues would go a long way toward solutions that meet the needs of all parties involved. There is not going to be a “one-size-fits-all” solution: rather, there could be several options available to employees and employers, and these options need to be clearly articulated.

The issue of the caregiver and his/her employment should also be brought to the forefront of insurance company and government plans. Employees and employers need to know the available options for helping caregivers whose loved one is having a relapse or is no longer able to work. As well, plans for caregivers need to be flexible in order to address their specific need at each particular stage of their loved one’s illness.

To optimally impact policy around employment issues for people living with MS, and for their caregivers, the issue would benefit from a strong lobby and/or advocacy group to work with the new federal government.

3. Public Awareness

A public awareness campaign is needed to bring MS to the forefront, similar to the work being done on mental health in the workplace. In particular, the episodic nature of MS, and its invisible symptoms, need to be highlighted so that employers and the general public know MS is so much more than just not being able to walk. This would reduce the stigma surrounding MS and encourage employers, and the colleagues of people living with MS or their caregivers, to be more accommodating...
and understanding. A public awareness campaign would improve the potential for fundraising to support employment initiatives if the public understood MS and how people have unique support requirements to continue to participate in the workforce.
CHAPTER 4
Key Messages

Chapter Summary

• Action is required by individuals, employers, the health care system, and governments (at the federal, provincial, and municipal levels) to support better quality of life and productivity among individuals with MS, as well as their caregivers.

• Flexibility on the part of individuals with MS and their employers could lead to greater workforce participation. This could benefit individuals financially and mentally, assist employers by way of productivity and retention of skills, and reduce pressure on government benefit programs.

• The way that financial and other supports are set up or perceived creates barriers to access. This prevents some people from taking full advantage of these supports to maximize their workforce participation. These barriers may be real or merely perceived—but are barriers, nonetheless.
Developing a strategy across provinces and territories may follow a similar approach to that developed in Alberta. As Alberta’s MS Partnership works toward achieving the recommendations outlined in *The Way Forward*,¹ lessons and best practices could be scaled and applied to the other provinces and territories.

In this chapter, we summarize insights regarding the actions required by stakeholders to support better QoL and productivity among individuals with MS, as well as their caregivers. We begin by separately listing actions most relevant to each stakeholder group: individuals, employers, the health care system, insurance companies, advocacy groups, and governments. Insights are supported by the literature referenced and findings discussed throughout this report. In addition, these insights reflect discussions held at the stakeholder workshop. (See Exhibit 3.)

**Actions for Specific Stakeholder Groups**

**Individuals**

- The limited evidence on communication of diagnosis to an employer suggests that this results in longer work tenure and more accommodations. When telling an employer about their MS, individuals can be clear about the type of accommodations that may allow them to continue working and being productive. An individual may be able to suggest resources for the employer, such as those offered by the MS Society of Canada, the Canadian Council on Rehabilitation and Work, and the federal government.
- Disease progression may be slowed and some MS symptoms improved through the appropriate use of interventions and strategies. These may allow individuals to retain their work productivity and employment for an extended period.

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• Individuals with MS and their families may need to take a proactive approach toward issues with employment, such as thinking through potential opportunities for re-training, looking for positions within their place of employment that may be more accommodating toward their particular set of needs and researching for themselves what their particular insurance company provides in terms of benefits, opportunities to re-train, and so forth.

• A willingness to re-train and/or try a different type of work that is still in line with the passions and abilities of the person with MS could result in a win-win solution.

• Individuals with MS are often the best source of information for communicating to their employer how their MS is affecting them and how they could potentially use their knowledge and skills in ways that would benefit both parties (e.g., working from home, working on a part-time basis, or moving their office closer to washroom facilities).

• The ins and outs of disability benefits are often not well-understood by persons with MS and their families. Life insurance benefits seem to be more straightforward, and individuals tend to sign up for this type of benefit more so than for the disability benefits. Individuals need to remember that they may need to enter the “retirement” phase of their life earlier than perhaps their colleagues. As such, persons with MS may need more financial resources to live well into their old age.

Employers

• By creating a culture of trust and openness, employers may encourage the communication of MS diagnosis by their employees. If this is met with a positive employer attitude and suitable accommodations, this can lead to greater employee retention. In this way, employers can reduce turnover and thereby retain the skills and experience of their employees. Accommodations may also benefit the employer by matching the employee to suitable tasks and projects, increasing efficiency.

• Providing opportunities for employees to re-train could be a useful strategy, as it would potentially allow employees to remain within the organization in a different capacity. Insurance companies may be a
resource for helping this to occur, so employers need to feel comfortable reaching out to the insurance companies to learn which options might be feasible.

- 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.
- Furthermore, employers could offer compassionate care benefits or group insurance that gives caregivers an income when they have to temporarily leave work because of their caregiving responsibilities. Again, this would make it easier for the caregiver to remain in the workforce in the long term.

**Health Care System**

- The health care system and the government need to make it easier for individuals with MS, and for their caregivers, to navigate the system of services and supports available to them.
- Vocational rehabilitation programs involving multidisciplinary providers should be offered. This type of service may be best delivered if providers already work in health teams, examples of which can be seen across Canada.
- There are 22 MS specialty clinics in Canada, dedicated to the care, support, and education of persons with MS and their families. These clinics can play an important role in helping persons with MS navigate the complex health care, insurance company, and government regulations around employment issues. The ability of the staff at the MS clinics to help in this regard would be greatly increased through information-sharing sessions with insurance companies and government agencies.
- More effective partnerships between the health care system and community organizations—such as the MS Society—could enhance the support given to people living with MS.
Governments

- Access to programs, benefits, and services is often linked to the definition of “disability” or the receipt of disability benefits. Governments can improve the ability of individuals living with MS to access these by explicitly including relapse-remitting MS—as well as other forms—within their definition of disability. This could allow individuals living with MS to work when they can, thereby increasing their contribution to the workforce, and reducing their overall requirements for benefits.
- All stakeholders, including the government, the health care system, and the private sector, should support research into how people with MS, and their caregivers, can be retained within work, or brought into it. This research should aim to develop a business case that considers the overall costs and benefits for all stakeholders.
- As well as research, governments and the private sector should work to enhance supports that aim to increase job retention and employment opportunities for people living with MS, and for their caregivers. This may, at least partially, be achieved by strengthening existing programs funded through the Labour Market Agreements for Persons With Disabilities.
- In relation to the above points, traditional research on the effectiveness of MS therapies could be extended to include outcomes related to workplace productivity.
- Provincial and international examples of caregiver supports—such as allowances, benefits, and stress reduction aids, along with proactive assessments to access—should be investigated.
- Small businesses may not have the resources to provide the same opportunities as large companies. Governments could help small businesses by helping with re-training programs and providing education on the various programs available for helping persons with MS.
- As with the health care system, the government could work more closely with community groups to provide better support for people living with MS.
Insurance Companies

- A greater transparency and focus on information-sharing with individuals with MS, employers, MS health care providers, and government and community organizations could open up new lines of communication for thinking through potential ways to re-train persons with MS in the workforce.

- Insurance companies play a critical role in the employment status of persons with MS, and not just in terms of paying disability benefits. They have a potentially greater role in helping persons to stay employed. Through the various programs they offer, their role and the opportunities they can provide beyond just disability benefits need to be better highlighted and understood.

- Clearer communication regarding the nature of the benefits that insurance companies provide and how they are meant to help individuals with MS may help dispel some of the confusion and frustration individuals with MS have with insurance companies.

- A review of current policies regarding what is considered sick or disabled may be needed for diseases such as MS in which there may well be times of sickness/disability and then times of wellness (i.e., episodic illness).

Tell us how we’re doing—rate this publication.

Exhibit 3
Recommendations to Support Improved Quality of Life and Productivity

<table>
<thead>
<tr>
<th>Individuals with MS and their caregivers</th>
<th>Employers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Consider disclosing to employer</td>
<td>• Understand individual’s capacity and needs</td>
</tr>
<tr>
<td>• Access available services and resources</td>
<td>• Create culture of trust and openness</td>
</tr>
<tr>
<td></td>
<td>• Provide adaptations/accommodations where appropriate</td>
</tr>
<tr>
<td></td>
<td>• Offer flexible or meaningful health insurance plans and employee benefits for patients and caregivers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health care system</th>
<th>Governments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Make navigating the system easier for patients</td>
<td>• Improve employment insurance benefits to support intermittent work capacity</td>
</tr>
<tr>
<td>• Provide referrals and information to other resources, including those provided in the community for people living with MS and their caregivers</td>
<td>• Improve access to social services</td>
</tr>
<tr>
<td></td>
<td>• Create a better support system for unpaid caregivers</td>
</tr>
<tr>
<td></td>
<td>• Fund more research, collect more data, and evaluate</td>
</tr>
</tbody>
</table>

Source: The Conference Board of Canada.
Research Objectives

The research objectives are to:

1. define “disability” and “burden” in the context of MS;
2. describe the benefits of delaying the onset of disability and reducing the burden of disability for those diagnosed with MS, their caregivers, employers, and governments;
3. identify effective ways (strategies) to delay the onset of disability and reduce the burden of disability in individuals living with MS;
4. identify best practices in terms of disease management, workplace policies, and programs that individuals living with MS need in order to be more successful in the workplace and to enjoy a better quality of life;
5. identify the barriers to and facilitators for implementing and achieving best results from these best practices.

Population(s)

1. The primary populations of interest are those individuals living with MS. The steering committee chose to focus on the following types of MS:
   - Relapsing-Remitting MS (RRMS): Approximately 85 per cent of individuals living with MS are initially diagnosed with RRMS. The condition is characterized by unpredictable but clearly defined relapses, attacks, exacerbations, or flare-ups. It is during relapse that
new symptoms appear or existing ones worsen. Between relapses is recovery, which is complete or nearly complete (the individual experiences pre-relapse function)—this is called remission.

- **Secondary-Progressive MS (SPMS):** This stage follows the diagnosis of RRMS. Distinct relapses and remissions become less apparent over time and the disease starts to progress steadily. About half of individuals with RRMS start to worsen within 10 to 20 years of diagnosis and will often experience increasing levels of disability.

- **Primary-Progressive MS (PPMS):** Individuals with PPMS experience a slow accumulation of disability without defined relapses. The condition may stabilize for periods of time. Individuals with PPMS may even experience temporary improvement. However, overall, there are no periods of remission. Approximately 10 per cent of individuals living with MS are diagnosed with this form of it.

2. Another population of interest included unpaid caregivers of individuals living with MS. (These are usually family members.)

3. An additional population of interest included individuals characterized as “actors of change”: specifically, groups that can identify and implement best practices to address research objectives 3 and 4. The specific focus of this work is the workplace/employers. Thus, the “actors of change” in this circumstance include employers as well as health insurers. In addition, certain government policies will influence workplace policies. Therefore, governments (provincial and territorial) would be included as relevant actors.

**Intervention(s)**

For the purposes of this proposed literature review, “interventions” are used loosely to describe the following (as taken from the specified research objectives):

- strategies to delay the onset of disability and reduce the burden of disability in individuals living with MS;
• best practices in terms of workplace/employer policies and programs that individuals living with MS need in order to be more successful and enjoy better QoL. These could include accommodations to enable retention of an existing role and/or re-training to a different role within the same organization.

Comparisons

Those studies that are experimental or quasi-experimental (i.e., observational) in nature will, in most cases, identify a control or comparator group when examining the impact of an intervention or strategies on the outcomes of interest. The comparison may be the impact of an intervention or multiple interventions (workplace policies and programs and government policies) versus a control intervention on outcomes for individuals living with MS. In some cases, the comparison may be the change (before and after) in outcome from baseline after the implementation of an intervention within a population group.

Outcomes

The outcomes of interest by population include the following:

**Individuals Living With MS**

• reduction in relapse/episodic symptoms;
• reduction in disability;
• improvements in QoL;
• improvements in employment engagement (ability to participate in the labour force, reduced absenteeism, improved presenteeism).

**Caregivers of Individuals Living With MS**

• improvements in QoL;
• improvements in employment engagement (ability to participate in the labour force, reduced absenteeism, improved presenteeism).
Employers
• improvements in employment engagement (ability to participate in labour force, reduced absenteeism, improved presenteeism);
• direct health care costs (health care services utilization).

Government
• improvements in productivity (economic benefits to the economy);
• direct health care costs (health care services utilization).

Search Strategy
The most recent searches were conducted on December 19, 2014.

1. Published literature searches started with the Medline electronic database for peer-reviewed medical/health research articles. A research librarian at the University of Ottawa (Jeanette Hatherill) was consulted to identify other key databases that would include literature on programs/policies in the workplace/employer to support individuals with MS and caregivers of individuals living with MS. It was suggested that ABI/Inform Global would be an appropriate database to search for health care management studies and would encompass much of the workplace wellness literature. These databases were used to identify the relevant published literature for the review. See tables 1 and 2 for details of these unique searches.

2. Grey literature included selected research reports and other unpublished work recommended by the steering committee. The method employed was a general Google search using key words. (The ABI/Inform database also includes dissertations and theses as well as conference papers and proceedings, which are considered grey literature.)

3. Reference lists of a selected number of relevant articles and reports were searched in order to identify any missed information after the initial published literature and grey literature search.

4. Published literature search keywords/MeSh: The following MeSh terms and keywords were used to identify relevant literature for this report.
Appendix A | The Conference Board of Canada

- multiple sclerosis
- multiple sclerosis, relapsing-remitting
- multiple sclerosis, primary-progressive
- multiple sclerosis, secondary-progressive
- disability evaluation/disability
- sick leave
- depression/anxiety
- absenteeism
- presenteeism
- productivity
- disclosure
- job retention
- health care utilization
- outcome assessment (health care)
- longitudinal studies
- disease progression

**Detailed Search Strategy**

**Inclusion Criteria**
The most recent research was prioritized in this research. In the search strategy, literature was included if it was published within the last 10 years, with preference for research published within the last five years. Sources of information included published research identified in electronic databases and reference lists, as well as grey literature (unpublished) in the form of reports.

Additionally, conference proceedings were eligible for inclusion. The review included relevant articles and reports that would help address the specific research objectives. For the first phase of screening the published literature, only research that was available in full text and had a structured abstract was included. Intervention-based studies were eligible for inclusion. For the purposes of this review, “interventions” included medical and non-medical therapies, programs, practices, policies; and regulation/legislation within the employment space, health care system, and government.
### Table 1
**ABI/Inform Global Search**

<table>
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<th>#</th>
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Source: The Conference Board of Canada.

### Table 2
**ABI/Inform Global Search**

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<td>Employee</td>
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<tr>
<td>3</td>
<td>Assistance</td>
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<tr>
<td>4</td>
<td>1 and 2 and 3</td>
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<tr>
<td>5</td>
<td>Limit 4 to English and published between 2004 and 2015</td>
<td>482</td>
</tr>
</tbody>
</table>

Source: The Conference Board of Canada.
Appendix A | The Conference Board of Canada

Exclusion Criteria

Literature that was not published in the English language and that was not published within the specific time frame was excluded. Studies that were laboratory-based or bio-physiological in nature were excluded.

Studies were excluded if they were too narrow (applied only to small subsets of the target populations); were established as weak evidence in the context of the review (e.g., pilot study); contained a small sample size; had very short follow-up; appeared to be highly biased; were older published individual studies in the context of already existing newer studies; or were reviews on the same subject.

Screening Phases

Once the full search strategy and appropriate filters were applied (date of publication and language), a rapid scan of document titles (screening Phase 1) and abstracts/executive summaries (screening Phase 2) were applied. The screening phases involved the application of the specific inclusion and exclusion criteria to identify which documents were to be included in the review synthesis.

Quality Assessment

Normally, a rigorous critical appraisal approach would be applied to the retained studies in a systematic review. For the purposes of this literature review, we weighed the quality of the information according to a hierarchy of evidence (ordered from best to lowest weight of evidence):

1. systematic reviews/meta-analyses
2. randomized controlled trial
3. cohort studies
4. case-control studies
5. cross-sectional studies
6. case studies
7. expert opinion/commentaries
The researcher also read the full text of each retained study and further filtered out any non-relevant documents—again applying the same inclusion/exclusion criteria to the full text.

**Knowledge Synthesis**

Once the final relevant documents were identified, a data extraction form was used to extract the relevant information. The information included an identifier or document reference; PICO (population, interventions, comparisons, and outcomes); and the findings and key messages. The extraction form is usually developed during the process of extracting information, often expanding with new data elements as the researcher assesses each included article.

The information was synthesized based on the data extracted. The synthesis was communicated as a narrative review with insights organized by themes that may be directly linked to the study objectives or which were specified in consultation with the steering committee.
APPENDIX B

The Value of Specialty Medications: An Employer Perspective

A report by The Conference Board of Canada, expected to be released in 2016, will focus on the economic value of specialty medications’ use in relation to their costs for employers.

This report provides a perspective about the use of specialty medications at the workplace. The report focuses on three chronic diseases: rheumatoid arthritis, Crohn’s disease, and multiple sclerosis. The purpose of the report is to model the costs and benefits of specialty medications for these three conditions at the workplace. The research includes both the treatment of the employee and dependents (spouse and children). The costs and benefits of treatment are modelled from the employer viewpoint as well as the societal perspective.

The study shows that employers of people with MS benefit through reductions in absenteeism and presenteeism and a reduced risk of long-term disability. While the added costs to the employer may be only partially offset by the benefits, it is also noted that a competitive and comprehensive benefit plan helps employers recruit and retain employees. The value of these benefits couldn't be included in the modelling work.
The societal benefits from employer-provided specialty medications were found to extend well beyond the workplace. In other words, there were considerable external effects associated with employer-provided coverage of specialty medications. The main benefits for society, in addition to those at the employer level, are reduced utilization of in- and out-patient health care resources.
APPENDIX C

Bibliography


Appendix C | The Conference Board of Canada


Rietberg, Marc B., and others. “Effects of Multidisciplinary Rehabilitation on Chronic Fatigue in Multiple Sclerosis: A Randomized Controlled Trial.” *PLOS ONE* 9, no. 9 (2014): e107710.


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