Cost of Caring: Implications for Family Caregivers
© Multiple Sclerosis Society of Canada, 2008
Disponible en français

The Cost of Caring Implications for family caregivers
Implications for family caregivers

References


2 Calling for a National Caregiving Policy: A Prerequisite for Providing Home and Community Care, Canadian Caregiver Coalition, 2002, page 1.


4 Claire is a pseudonym. Her physician contributed her story.


7 George is a pseudonym. His physician contributed his story.

Approved: Multiple Sclerosis Society of Canada, National Executive Committee, October 23, 2007
The Cost Of Caring

valuable contribution of caregivers.

- **Expand the criteria** of the current Employment Insurance Compassionate Care Benefits and the related job protection beyond the current six-week period to include chronic or episodic caregiving periods.
- **Amend the Canada Labour Code** to grant leave and job protection to caregivers.
- **Encourage employers** through tax credits and other incentives to **promote positive, family friendly programs for caregivers** in their workplaces including the continuation of employment benefits such as pension, sick leave and vacation entitlements during a caregiving leave.
- **Include caregivers who have had to drop out of the workforce for an extended period of time in government-supported training programs.**
- **Enhance existing tax credits and deductions** for caregivers to recognize the very real expenses of taking care of someone at home.
- **Allow spouses to claim the caregiver tax credit** currently they are not eligible for this small credit even though they are the primary caregivers.

**Long-term**

- The federal/provincial/territorial governments should initiate the development of a cross-Canada caregiving strategy in partnership with caregivers and organizations representing caregivers. Key aspects of the caregiving strategy should include:
  - Provision of financial remuneration for caregivers;
  - Provision of family support programs including childcare and respite services at a reasonable cost;
  - Provision of psychosocial support for caregivers such as a help line;
  - Provision of education and training programs on caregiving for caregivers;
  - Develop and support cross-Canada research on caregiving;
  - Develop and support an Office for Caregiving Issues to be the central point for carrying out the National Caregiving Strategy.

**Looking Ahead**

The Multiple Sclerosis Society of Canada has conducted two major caregiver projects in the past five years. Key findings were:

- **Caregivers** rated highly receiving external recognition, acknowledgement and appreciation of the caregiver role.
- **Caregivers** reported they prefer to choose the service or activity that would meet their caregiving-related needs.
- **Caregivers** reported they have significant financial security concerns because of the direct and indirect caregiving-related costs they incurred.

Another important finding reported by caregivers was the lack of information and resources in the community, making the navigation of the health care system extremely frustrating and overly complex. They also said that greater collaboration is required among governments to ensure caregivers are able to find appropriate information about caregiving and health services. This is vital in a country with multiple levels of government.

The Cost of Caring

**The Cost of Caring**: Implications for family caregivers

Voluntary caregivers are the invisible and unsung heroes that allow the Canadian health care system to function. According to the Canadian Caregiver Coalition, an estimated three million Canadians are caregivers providing care and assistance for their family members and friends who are ill, injured or have a disability. They prepare meals, do cleaning, transport and accompany loved ones to medical appointments, manage financial matters and provide both personal and specialized medical care. Caregivers contribute more than $5 billion of unpaid labour annually to the health care system and save governments millions of dollars in annual costs for hospitalization, long-term institutional care and home care.

Looking specifically at issues related to multiple sclerosis, caregivers have an important role in enabling people with MS to remain in their homes and communities. Multiple sclerosis provides particular challenges to those who develop it and their caregivers since it is most often a disease of young adults. MS is a disease of the brain and spinal cord which most often strikes between the ages of 15 and 40. The disease is often episodic in nature, especially in the first 10 to 15 years, when it is characterized by unpredictable relapses (also called attacks), followed by periods of remission. It can affect vision, coordination, balance and mobility, mood and cognition, and cause severe fatigue. Over time, the disease often becomes worse with fewer periods of remission. Often, the resulting disability becomes permanent.

**MS Society Caregiver Findings**

The Multiple Sclerosis Society of Canada has conducted two major caregiver projects in the past five years. Key findings were:

- **Caregivers**, most often spouses, are integral to the health and well being of people with MS.
- **More than one half of caregivers** surveyed reported that caregiving has a negative effect on their own health.
- **Caregivers** reported significant financial security concerns because of the direct and indirect caregiving-related costs they incurred.

The Multiple Sclerosis Society of Canada is grateful for the leadership of the Canadian Caregiver Coalition and for its excellent research in succinctly outlining the issues.

According to the Canadian Caregiver Coalition, an estimated three million Canadians are caregivers providing care and assistance for their family members and friends who are ill, injured or have a disability. They prepare meals, do cleaning, transport and accompany loved ones to medical appointments, manage financial matters and provide both personal and specialized medical care. Caregivers contribute more than $5 billion of unpaid labour annually to the health care system and save governments millions of dollars in annual costs for hospitalization, long-term institutional care and home care.

Looking specifically at issues related to multiple sclerosis, caregivers have an important role in enabling people with MS to remain in their homes and communities. Multiple sclerosis provides particular challenges to those who develop it and their caregivers since it is most often a disease of young adults. MS is a disease of the brain and spinal cord which most often strikes between the ages of 15 and 40. The disease is often episodic in nature, especially in the first 10 to 15 years, when it is characterized by unpredictable relapses (also called attacks), followed by periods of remission. It can affect vision, coordination, balance and mobility, mood and cognition, and cause severe fatigue. Over time, the disease often becomes worse with fewer periods of remission. Often, the resulting disability becomes permanent.

**The Multiple Sclerosis Society of Canada is grateful for the leadership of the Canadian Caregiver Coalition and for its excellent research in succinctly outlining the issues.**
endorse the guiding principles developed by Any program to support caregivers must start what is needed for caregivers. Australia, in Germany, Japan, and the Netherlands have developed national caregiving strategies in recent years, there has been more recognition of the importance of caregivers by various levels of governments. The 2003 First Ministers’ Accord on Health Care Renewal included two positive though limited programs: short-term acute home care coverage and Employment Insurance Compassionate Care Benefits. However, Canadian federal and provincial governments can do much more and can learn from other jurisdictions. Internationally, the United States, Great Britain, Australia, Germany, Japan and the Netherlands have developed national caregiving strategies or supports for caregivers. Australia, in particular, funds caregiver resource centres in each state and territory and provides caregiver allowances and payments.

What is Needed
Any program to support caregivers must start with caregivers themselves. The MS Society endorses the guiding principles developed by the Canadian Caregiver Coalition: Caregivers are acknowledged, respected and valued. Caregivers have a choice to become partners in care. Caregivers have a voice in all decisions that affect them. Caregivers require support. What this means is that all levels of government in Canada, organizations that support caregivers and caregivers themselves should work together to: Ensure that social and health care services are delivered based on the need of the individual who is ill or disabled and not on the availability of caregivers or family income level. Ensure that financial security of caregivers is not compromised. Develop a cross-Canada program to inform Canadians about caregiving and the important role of caregivers. Develop information and education programs about caregiving and promote the programs to caregivers.

Personal Story: Feeling guilty
Although Claire was fiercely independent, her limited vision required her to depend on her spouse to drive her to numerous medical appointments. Unfortunately, her husband’s employer was not sympathetic. Her husband was reprimanded for missing work even though he was not paid for the time off and threatened with dismissal. Claire was forced to choose carefully which appointments she would make and called on friends to help out, but unpredictable winter weather and others’ busy lives, continue to make Claire feel guilty for having to depend on so many others.

Programs for Caregivers
In recent years, there has been more recognition of the importance of caregivers by various levels of governments. The 2003 First Ministers’ Accord on Health Care Renewal included two positive though limited programs: short-term acute home care coverage and Employment Insurance Compassionate Care Benefits. However, Canadian federal and provincial governments can do much more and can learn from other jurisdictions. Internationally, the United States, Great Britain, Australia, Germany, Japan and the Netherlands have developed national caregiving strategies or supports for caregivers. Australia, in particular, funds caregiver resource centres in each state and territory and provides caregiver allowances and payments.

Financial Needs
The financial needs of caregivers are often overlooked. Currently, caregivers who must stop work to care for someone who is disabled are penalized. Not only do they face a loss of income when they leave the workforce, but they compromise the future level of their pension at retirement. In addition, many caregivers are not in the paid workforce, but they provide a service that benefits society as a whole. Caregiver financial support should be addressed by making changes to current federal income programs and tax deductions and credits. On a longer-term basis, the Canadian Caregiver Coalition has recommended as part of a national caregiver strategy that a national insurance plan for long-term care be developed to provide direct caregiver financial support.

The Multiple Sclerosis Society of Canada supports the development of an overall caregiver strategy. The MS Society also suggests that the development of a caregiver strategy be undertaken through a phased approach. Accordingly, our recommendations take into account short-term approaches, which can build upon existing programs, and long-term approaches, which require the development of new programs involving multiple levels of government and other partners.

Specific Recommendations
Short-term
• To prevent the caregiver from being penalized during times of non-contribution to CPP or QPP, allow an averaged contribution to be applied during periods of caregiving.
• Alternatively, or in addition, allow a caregiving dropout provision for CPP benefits similar to the child-care dropout. The caregiving dropout should be in addition to the current practice of automatically dropping out the 15 percent of the contributory period in which earnings were lowest. This would prevent the caregiver being penalized and recognize the

Personal Story: Caregiver depression
When George quit his job to provide full-time care for his wife, he had no idea how his life would change. Financially, they were okay although they had to scale down. He felt proud about his decision. A year later, George was experiencing depression. He loved his wife dearly and didn’t regret the decision, but he missed the stimulus of his previous job. His days were filled with the endless routine of caregiving and household chores. Friends no longer stopped by. He lost confidence and could no longer see beyond the caregiver role. He too had become disabled by the effects of multiple sclerosis.
The Canadian Caregiver Coalition endorses the guiding principles developed by caregivers themselves. The MS Society of Canada also supports the development of an overall strategy that a national insurance plan for caregiver financial support should be addressed by making changes to current federal income programs and tax deductions and credits. On a longer-term basis, the Canadian Caregiver Coalition has recommended as part of a national caregiver strategy that a national insurance plan for long-term care be developed to provide direct caregiver financial support.

The Multiple Sclerosis Society of Canada supports the development of an overall caregiver strategy. The MS Society also suggests that the development of a caregiver strategy be undertaken through a phased approach. Accordingly, our recommendations take into account short-term approaches, which can build upon existing programs, and long-term approaches, which require the development of new programs involving multiple levels of government and other partners.

Financial Needs

The financial needs of caregivers are often overlooked. Currently, caregivers who must stop work to care for someone who is disabled are penalized. Not only do they face a loss of income when they leave the workforce, but they compromise the future level of their pension at retirement. In addition, many caregivers are not in the paid workforce, but they provide a service that benefits society as a whole. Caregiver financial support should be addressed by making changes to current federal income programs and tax deductions and credits. On a longer-term basis, the Canadian Caregiver Coalition has recommended as part of a national caregiver strategy that a national insurance plan for long-term care be developed to provide direct caregiver financial support.

The Multiple Sclerosis Society of Canada supports the development of an overall caregiver strategy. The MS Society also suggests that the development of a caregiver strategy be undertaken through a phased approach. Accordingly, our recommendations take into account short-term approaches, which can build upon existing programs, and long-term approaches, which require the development of new programs involving multiple levels of government and other partners.

Specific Recommendations

Short-term

- To prevent the caregiver from being penalized during times of non-contribution to CPP or QPP, allow an averaged contribution to be applied during periods of caregiving.
- Alternatively, or in addition, allow a caregiving dropout provision for CPP benefits similar to the child-care dropout. The caregiving dropout should be in addition to the current practice of automatically dropping out the 15 percent of the contributory period in which earnings were lowest. This would prevent the caregiver being penalized and recognize the

Programs for Caregivers

In recent years, there has been more recognition of the importance of caregivers by various levels of governments. The 2003 First Ministers’ Accord on Health Care Renewal included two positive though limited programs: short-term acute home care coverage and Employment Insurance Compassionate Care Benefits. However, Canadian federal and provincial governments can do much more and can learn from other jurisdictions. Internationally, the United States, Great Britain, Australia, Germany, Japan and the Netherlands have developed national caregiving strategies or supports for caregivers. Australia, in particular, funds caregiver resource centres in each state and territory and provides caregiver allowances and payments.  What is Needed

Any program to support caregivers must start with caregivers themselves. The MS Society endorses the guiding principles developed by the Canadian Caregiver Coalition:

- Caregivers are acknowledged, respected and valued.
- Caregivers have a choice to become partners in care.
- Caregivers have a voice in all decisions that affect them.
- Caregivers require support. What this means is that all levels of government in Canada, organizations that support caregivers and caregivers themselves should work together to:
  - Ensure that social and health care services are delivered based on the need of the individual who is ill or disabled and not on the availability of caregivers or family income level.
  - Ensure that financial security of caregivers is not compromised.
  - Develop a cross-Canada program to inform Canadians about caregiving and the important role of caregivers.
  - Develop information and education programs about caregiving and promote the programs to caregivers.

A year later, George was experiencing depression. He loved his wife dearly and didn’t regret the decision, but he missed the stimulus of his previous job. His days were filled with the endless routine of caregiving and household chores. Friends no longer stopped by. He lost confidence and could no longer see beyond the caregiver role. He too had become disabled by the effects of multiple sclerosis.

Implications for family caregivers

Personal Story: Feeling guilty

Although Claire was fiercely independent, her limited vision required her to depend on her spouse to drive her to numerous medical appointments. Unfortunately, her husband’s employer was not sympathetic. Her husband was reprimanded for missing work even though he was not paid for the time off and threatened with dismissal. Claire was forced to choose carefully which appointments she would make and called on friends to help out, but unpredictable winter weather and others’ busy lives, continue to make Claire feel guilty for having to depend on so many others.

What is Needed

Any program to support caregivers must start with caregivers themselves. The MS Society endorses the guiding principles developed by the Canadian Caregiver Coalition:

- Caregivers are acknowledged, respected and valued.
- Caregivers have a choice to become partners in care.
- Caregivers have a voice in all decisions that affect them.
- Caregivers require support. What this means is that all levels of government in Canada, organizations that support caregivers and caregivers themselves should work together to:
  - Ensure that social and health care services are delivered based on the need of the individual who is ill or disabled and not on the availability of caregivers or family income level.
  - Ensure that financial security of caregivers is not compromised.
  - Develop a cross-Canada program to inform Canadians about caregiving and the important role of caregivers.
  - Develop information and education programs about caregiving and promote the programs to caregivers.

Personal Story: Caregiver depression

When George quit his job to provide full-time care for his wife, he had no idea how his life would change. Financially, they were okay although they had to scale down. He felt proud about his decision. A year later, George was experiencing depression. He loved his wife dearly and didn’t regret the decision, but he missed the stimulus of his previous job. His days were filled with the endless routine of caregiving and household chores. Friends no longer stopped by. He lost confidence and could no longer see beyond the caregiver role. He too had become disabled by the effects of multiple sclerosis.
The Cost Of Caring

valuable contribution of caregivers.

- **Expand the criteria** of the current Employment Insurance Compassionate Care Benefits and the related job protection beyond the current six-week period to include chronic or episodic caregiving periods.

- **Amend the Canada Labour Code** to grant leave and job protection to caregivers.

- **Encourage employers through tax credits and other incentives to promote positive, family friendly programs for caregivers** in their workplaces including the continuation of employment benefits such as pension, sick leave and vacation entitlements during a caregiving leave.

- **Include caregivers who have had to drop out of the workforce for an extended period of time in government-supported training programs.**

- **Enhance existing tax credits and deductions for caregivers** to recognize the very real expenses of caregivers. Key aspects of the caregiving strategy should include:
  - Provision of financial remuneration for caregivers;
  - Provision of family support programs including childcare and respite services at a reasonable cost;
  - Provision of psychosocial support for caregivers such as a help line;
  - Provision of education and training programs on caregiving for caregivers;
  - Develop and support cross-Canada research on caregiving;
  - Develop and support an Office for Caregiving Issues to be the central point for carrying out the National Caregiving Strategy.

Looking Ahead

The MS Society is committed to developing programs and sharing information that can support caregivers and to collaborating with external partners. It is vital that all stakeholders be involved to develop the kinds of programs that will support caregivers and care recipients from coast to coast. The MS Society looks forward to being part of and helping lead this important dialogue.

The Multiple Sclerosis Society of Canada is grateful for the leadership of the Canadian Caregiver Coalition and for its excellent research in succinctly outlining the issues.

The Cost of Caring: Implications for family caregivers

Voluntary caregivers are the invisible and unsung heroes that allow the Canadian health care system to function. According to the Canadian Caregiver Coalition, an estimated three million Canadians are caregivers providing care and assistance for their family members and friends who are ill, injured or have a disability. They prepare meals, do cleaning, transport and accompany loved ones to medical appointments, manage financial matters and provide both personal and specialized medical care. Caregivers contribute more than $5 billion of unpaid labour annually to the health care system and save governments millions of dollars in annual costs for hospitalization, long-term institutional care and home care.

Looking specifically at issues related to multiple sclerosis, caregivers have an important role in enabling people with MS to remain in their homes and communities. Multiple sclerosis provides particular challenges to those who develop it and their caregivers since it is most often a disease of young adults. MS is a disease of the brain and spinal cord which most often strikes between the ages of 15 and 40. The disease is often episodic in nature, especially in the first 10 to 15 years, when it is characterized by unpredictable relapses (also called attacks), followed by periods of remission. It can affect vision, coordination, balance and mobility, mood and cognition, and cause severe fatigue. Over time, the disease often becomes worse with fewer periods of remission. Often, the resulting disability becomes permanent.

**MS Society Caregiver Findings**

The Multiple Sclerosis Society of Canada has conducted two major caregiver projects in the past five years. Key findings were:

- Caregivers, most often spouses, are integral to the health and well being of people with MS.
- More than one half of caregivers surveyed reported that caregiving has a negative effect on their own health.
- Caregivers reported significant financial security concerns because of the direct and indirect caregiving-related costs they incurred.
- Caregivers rated highly receiving external recognition, acknowledgement and appreciation of the caregiver role.

Another important finding reported by caregivers was the lack of information and resources in the community, making the navigation of the health care system extremely frustrating and overly complex. They also said that greater collaboration is required among governments to ensure caregivers are able to find appropriate information about caregiving and health services. This is vital in a country with multiple levels of government.
References


2 Calling for a National Caregiving Policy: A Prerequisite for Providing Home and Community Care, Canadian Caregiver Coalition, 2002, page 1.


4 Claire is a pseudonym. Her physician contributed her story.


7 George is a pseudonym. His physician contributed his story.

Approved: Multiple Sclerosis Society of Canada, National Executive Committee, October 23, 2007
Cost of Caring:
Implications for Family Caregivers
© Multiple Sclerosis Society of Canada, 2008
Disponible en français