



Title: Resources for Family Caregivers

Article

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“Caregivers voluntarily provide care, services, or support, without remuneration to a person close to them, having one or more temporary or permanent disabilities (accident, handicap, illness, aging, etc.) and with which they have an emotional bond (father, mother, spouse, child, brother, sister, neighbor, friend, etc.) This is an additional role.”¹

According to the Government of Canada, in 2012, 46% of Canadians over the age of 15, or 13 million people, had provided some form of care to a member of the family or a friend with long-term health problems, disabilities or problems related to aging. Of this number, 28% of family caregivers provided care to a terminally ill person.²

The role played by informal caregivers is a cornerstone of the health system. Indeed, the current trend in the healthcare system is the promotion of home care. According to the RANQ (Regroupement des aidants naturels du Québec), "it would cost between \$ 4 billion and \$ 10 billion, and it would be necessary to hire 1.2 million full-time

professionals to replace the hours worked by informal caregivers.”³ It is therefore obvious that for the healthcare system, home care has significant benefits, including important savings in regards to care costs. Many patients and caregivers also prefer this alternative, but it is not without its challenges. These challenges include, among others, the exhaustion and impoverishment of family caregivers, the difficulty of reconciling caring duties with other responsibilities such as a career, family, and ongoing studies, as well as the lack of resources for home care services.⁴

More specifically, this article looks at family caregivers providing end-of-life care to a loved one. As previously mentioned, 28% of family caregivers identified in Canada provide care to a terminally ill relative.⁵ It is estimated that caregivers must spend an average of 54 hours per week caring for a terminally ill relative. It is important to collectively recognize and value the essential role of caregivers in the terminal phase of the disease. Indeed, according to the Canadian Hospice Palliative Care Association “caregivers are an integral part of the provision of care in all contexts. Care provided by families allows people to stay home longer or enhances the services offered in health care settings.”⁶ Concurrently, family caregivers experience great psychological, physical and financial stress, see their well-being decline and, in addition, have to deal with bereavement.⁷ That being said, despite the demands of caring for a loved one with a terminal illness, caregivers who have received adequate support at home from the healthcare system say they are satisfied with their caregiving experience, and feel appreciated for their contribution.⁸ It is essential that this support be offered early in the course of the disease, so that caregivers are better equipped to help their loved ones as the disease progresses. Moreover, the Canadian strategy for natural caregivers of the *Canadian Caregivers Coalition* has defined five priorities identified by caregivers in order to help them and support them in their role.⁹

- 1) safeguard the health and well-being of caregivers and increase the flexibility and availability of respite care
- 2) minimize the heavy financial burden on caregivers
- 3) promote access to user-friendly information and education
- 4) promote flexible workplaces and respect for caregivers' obligations
- 5) invest in research on the issue of family caregivers to enable evidence-based decision making on areas of support required.

To address these priorities, we have compiled a list of information and educational resources for families, patients and caregivers. This list also contains resources for respite services, and information on accessing financial support for family caregivers. Caregivers remain key players in the healthcare system, it is therefore essential to provide them with adequate support early in their involvement as a caregiver to a loved one.

Resources: information and education

CHPCA Handbook: “Guiding Family Caregivers of People at the End of Life”
The aim of the service was to provide family caregivers with knowledge, support, and resources in order to empower them to provide care and to adjust in the first months of bereavement.¹⁰

<https://www.chpca.ca/knowledge/guiding-family-caregivers-of-people-at-the-end-of-life-a-handbook-2016/>

APPUI: Several guides for Caregivers including “Maintaining life balance while caregiving” and “Support Guide for Caregivers : Palliative and end-of-life accompaniment”.¹¹

<https://www.lappui.org/en/Practical-tips/Guides-for-caregivers>

Palli-science: Francophone portal dedicated to enhancing palliative care provided in all care sectors. Section specifically made for patients and caregivers containing webinars, clinical tools, podcasts and videos.¹²

<https://palli-science.com/>

RANQ: Regroupement des aidants naturels du Québec. Released a press release in the impact of the pandemic on informal caregivers. Offers many webinars and articles in both French and English on the various resources available to caregivers and how to access them.¹³

<https://ranq.qc.ca/en/>

Pallium Canada: National non-profit organization focused on building professional and community capacity to help improve the quality and accessibility of palliative care in Canada. Offers many classes and webinars.¹⁴

<https://www.pallium.ca/>

Canadian Virtual Hospice: Information on palliative care, caregiving, disease progression and bereavement.¹⁵

<https://www.virtualhospice.ca/>

Resources: Respite care (and other services)

APPUI: repertoire of resources per territory, includes respite, information and documentation, training activities, support resources, legal and fiscal information, home care and transport resources.¹⁶

<https://www.lappui.org/en/Find-resources/Resource-directory>

Maison St-Raphaël: Day Centre offering professional, psychosocial and other services for guests and their caregivers.¹⁷

<https://maisonstraphael.org/centre-de-jour-de-soins-palliatifs/>

Novaide: Respite services for caregivers.¹⁸

<https://novaide.com/en/service/caregiver-respite/>

Nova Montréal: Non-profit organization offering home care including respite services.¹⁹
<https://www.novasoinsadomicile.ca/>

Resources : Financial Support

Compassionate Care Benefits²⁰

Possibility of receiving financial assistance for a duration of up to 26 weeks to allow a caregiver to provide care to a relative who is terminally ill.

<https://www.canada.ca/en/services/benefits/ei/caregiving.html>

Endnotes

¹ <https://ranq.qc.ca/procheaidante/>

² <https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-fra.htm>

³ <https://ranq.qc.ca/services/statistiques/>

⁴ <https://ranq.qc.ca/services/statistiques/>

⁵ http://www.hpcintegration.ca/media/37046/twf-valuing-caregivers-report-final_fr-2.pdf

⁶ http://www.hpcintegration.ca/media/37046/twf-valuing-caregivers-report-final_fr-2.pdf

⁷ <https://www.acsp.net/connaissance/guider-les-proches-aidantes-de-personnes-en-fin-de-vie/>

⁸ http://www.hpcintegration.ca/media/37046/twf-valuing-caregivers-report-final_fr-2.pdf

⁹ <http://ccc-ccan.ca/>

¹⁰ <https://www.acsp.net/connaissance/guider-les-proches-aidantes-de-personnes-en-fin-de-vie/>

¹¹ <https://www.lappui.org/Conseils-pratiques/Guides-pour-les-proches-aidants>

¹² <https://palli-science.com/patients-et-proches>

¹³ <https://ranq.qc.ca/formations-webinaire/>

¹⁴ <https://www.pallium.ca/about-pallium/>

¹⁵ https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

¹⁶ <https://www.lappui.org/Trouver-des-ressources/Repertoire-des-ressources>

¹⁷ <https://maisonstraphael.org/>

¹⁸ <https://novaide.com/en/home/>

¹⁹ <https://www.novasoinsadomicile.ca/>

²⁰ <https://www.canada.ca/fr/services/prestations/ae/proches-aidants/admissibilite.html>