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Providing support to caregivers who enable aging in place: An environmental scan and key interviews



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Acknowledgements

We acknowledge and greatly appreciate the perspectives provided by representatives from the organizations who participated in one-on-one interviews.

Interviewee organizations included:

- Baluchon Répit long terme
- Canadian Centre for Caregiving Excellence
- Family Services Toronto
- McMaster University
- Ontario Caregiver Organization
- University of Alberta



Executive Summary

About the project

As part of their work on reimagining excellence in care for older adults living at home, HEC acknowledges that caregivers play a critical role. To find out more about supports for these essential caregivers, HEC commissioned an environmental scan of organizations as well as interviews with representatives from organizations that provide programming to support caregivers who enable aging in place.

- **Project aim:** The aim of the project was to explore the breadth and depth of existing programming supports for caregivers who enable aging in place and to identify gaps and common practices. HEC will integrate the findings of this report into our Enabling Aging in Place Program.

About the methodology

- **Environmental scan:** The environmental scan was conducted between August-September 2023. The scan involved searching, accessing, and reviewing online information to find examples of no-cost Canadian programs that focused on support for caregivers who enable aging in place.
- **Individual interviews:** We conducted seven interviews with key individuals during September-October 2023. 6 Interviews were conducted in English and 1 in French.

Key findings

Information about caregiving is widely available online. Typically, this information focuses on how to provide caregiving and tips for self care.

Support to access services and peer support are also available. Some organizations also provide a 24-hour access hotline.

Some caregivers have access to more support than others. While online support is widely available, access to other supports such as respite, in-person peer and counselling support, and financial supports vary by region.

Potential areas for more support

Despite the variety of supports offered, some gaps in support exist. Areas where more support is needed include the following:

- **increased awareness of the important role that caregivers play,** and how this role may be acknowledged. Health care professionals, employers, and fellow employees, may benefit from training in this area.
- **continuous funding to support caregiver programming** across the care giving continuum. Advocacy efforts may help secure funding for organizations that support caregivers.
- **support for carers with unique needs** including youth, Indigenous caregivers, 2SLGBTQIA+, older adults, dual caregivers, and caregivers in remote communities.
- **respite** to ensure caregivers have temporary relief and to help prevent burnout.
- **financial aid** to reduce financial strain due to reduced work hours or added expenses.

Purpose and approach

Background

About HEC

Healthcare Excellence Canada (HEC) was created in 2021 as an amalgamation of the Canadian Patient Safety Institute and Canadian Foundation for Healthcare Improvement. Through collaboration with patients, caregivers, and people working in healthcare, HEC turns proven innovations into lasting improvements across all dimensions of healthcare. HEC works to spread innovations, build capability, and catalyze policy changes so that everyone in Canada has safe and high-quality healthcare.

Project background and aim

In the report, [Shaping the Future of Care Closer to Home for Older Adults](#), HEC reported findings from an environmental scan of programs across Canada that support aging in place. The findings showed that caregivers play a crucial role in enabling older adults to age in place. To learn more about programs that support this crucial role, HEC engaged Cathexis to conduct an environmental scan of programs across Canada that support caregivers who enable aging in place. In addition, HEC also engaged in interviews with representatives from organizations that provide this type of programming.

The aim of the project was to explore the breadth and depth of existing caregiver support programs for caregivers that enable aging in place. HEC will integrate the findings of this report into our Enabling Aging in Place Program.

About this report

This report describes our approach to the project, findings from an environmental scan of programs that support caregivers who enable aging in place, and a summary of 7 interviews with individuals from 6 organizations.

What does age in place mean?

According to Employment and Social Development Canada, aging in place means “having access to services and the health and social supports you need to live safely and independently in your home or your community for as long as you wish or are able.”

- Definition from [Government of Canada](#)

An exploratory approach

We took an exploratory approach to understanding support for caregivers who enable aging in place.

Aim and scoping questions

In consultation with HEC, we developed the following guiding questions:

- What programs exist in communities across Canada to support caregivers who enable aging in place?
- What are common or promising practices that support those who care for older adults to age in place?

Inclusion and exclusion criteria

We also developed a list of inclusion and exclusion criteria to narrow the scope of our search.

- **Included:** Programs that support unpaid caregivers, including family, friends, or neighbours, with a focus on supporting aging in place.
- **Excluded:** Programs that support paid caregivers e.g., PSWs

Methods

We explored existing programs through an environmental scan and one-on-one interviews.

Environmental scan

The environmental scan involved searching, accessing, and reviewing online information from organizations that had programs to support caregivers who support aging in place. These caregivers included family, friends and neighbours but excluded paid care providers. The scan explored whether programs had support in the following areas:

- Information
- Support to access services (e.g., resource database)
- Social/peer support
- Financial support
- Respite care
- 24/7 Helpline
- Advocacy

One-on-one interviews

Through the environmental scan and with contacts from HEC, we identified individuals from organizations in Canada that provide support to caregivers. HEC sent an introductory email to individuals and Cathexis followed-up to schedule and conduct interviews. We conducted a total of 7 interviews with key individuals across Canada. See Appendix A for the full interview guide.

Scoping the scan

Search Strategy

When conducting the environmental scan, we used Google incognito mode to ensure findings were not restricted by geography and previous searches. See Figure 1 for stages in the scan.

In addition to the term “aging in place”, we use the following search terms:

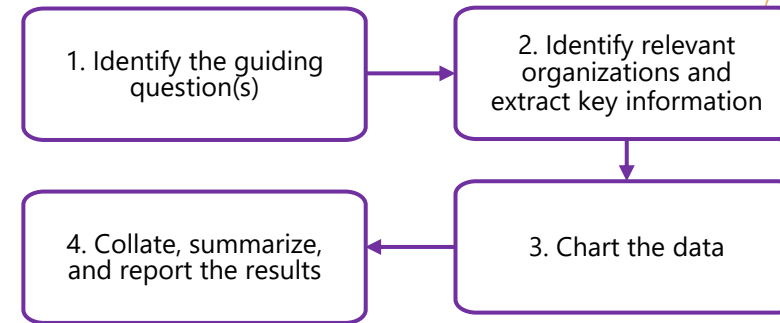
- Caregiver support programs Canada
- Caring for seniors in their home
- Caregiver/family supports and services
- Respite supports
- Financial aid for caregivers Canada
- Bereavement care for caregivers

Scope

To scope our findings, we focused on organizations that provide support in the following areas:

- Canadian programs
- Support for family, friends, neighbours that are caregivers
- Older adult caregiving
- Respite programs
- Programs or practices that fit within governmental programs

Figure 1. Stages in the environmental scan



Limitations

Please consider the following limitations when interpreting the report findings:

- The search was exploratory and time-bound and the list of program examples may not be exhaustive. Nonetheless, we are confident we captured an illustrative snapshot of current programs offering free support to caregivers who enable aging in place in Canada.
- Search results do not capture programs introduced after September 14, 2023
- This project did not set out to capture the voices of caregivers and a limited number of interviews with organizations were conducted, so there may be missed insights.

Findings: Environmental scan

Organizations that support unpaid caregivers

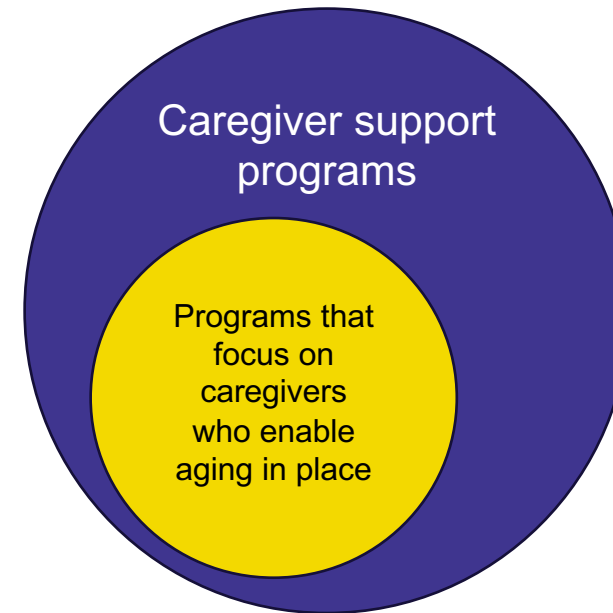
In our search, we discovered that many organizations support caregivers but fewer exclusively support unpaid caregivers that enable aging in place.

The scan identified **23 organizations offering programs focused on supporting unpaid caregivers that enable aging in place.** In practice, it was difficult to detangle supports that are intended exclusively for caregivers who enable aging in place from those offered to all types of caregivers. In conducting the scan, we noted information from an additional 33 Canadian organizations that offer caregiver support programs, which caregivers who enable aging in place can access (see Figure 2). However, the database does not provide an exhaustive list of all caregiver support organizations across Canada.

We extracted the following data from organizational websites:

- Name of organization
- Primary location
- Name(s) of program(s) offered
- Summary of program
- Types of support offered

Figure 2. We identified 23 organizations that offer programs with a focus on aging in place.



See Appendix B for a list of organizations by area of focus

Locations of organizations

Programs were identified at the regional, provincial, territorial and national level. See Appendix C for a full list of organizations providing programs. Below is a summary of organizations by geographical area.

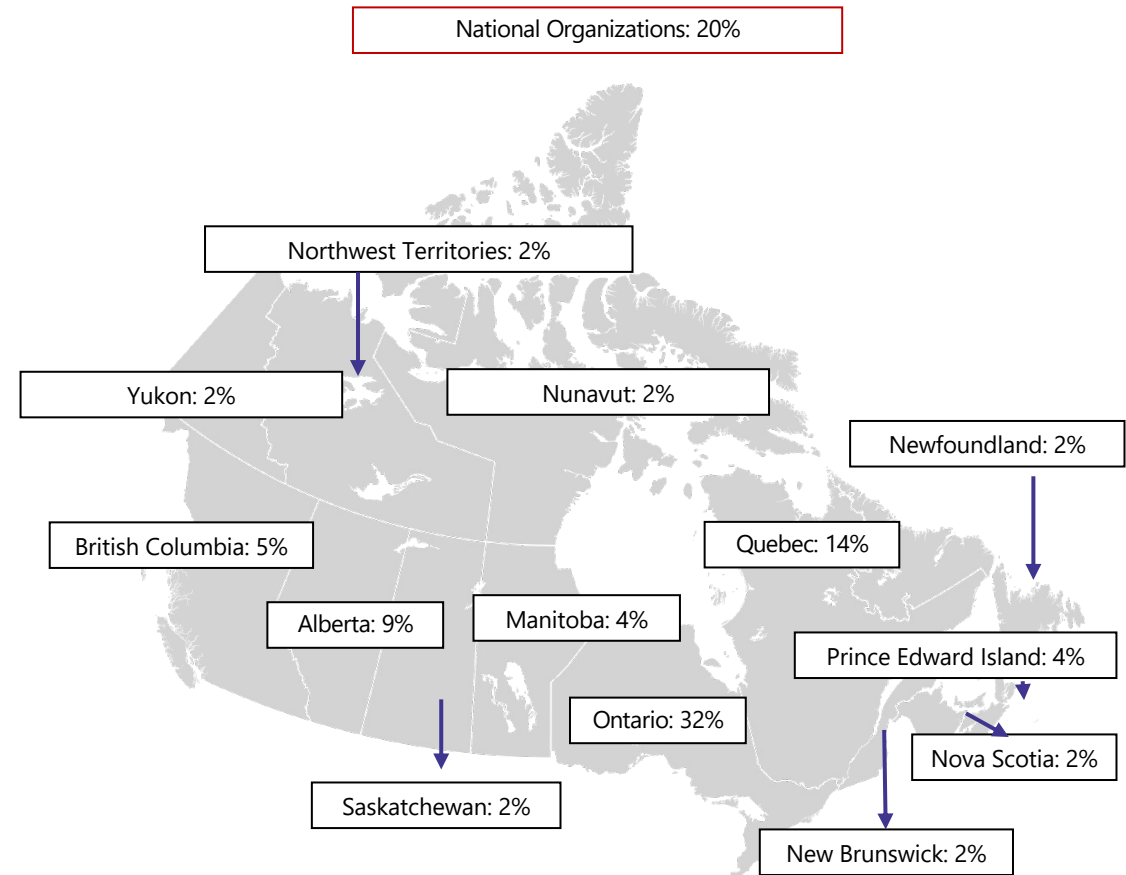
Provincial and Territorial

- 18 from Ontario
 - (includes 2 reviewed at the regional level – Toronto and Peel)
- 8 from Quebec
- 5 from Alberta
- 3 from BC
- 2 from Prince Edwards Island
- 2 from Manitoba
- 1 from Yukon
- 1 from Saskatchewan
- 1 from New Brunswick
- 1 from Newfoundland
- 1 from Nova Scotia
- 1 from Nunavut
- 1 from Northwest Territories

National

- 11 national organizations (offer services in multiple provinces)

Figure 3. Distribution of organizations by geographical location (n=56)



Types of support provided

Programs offered different types of support. Here we describe each type of support, listed from most to least frequently offered.

1. Information and resources

Access to information was the most commonly offered support. Information supports included educational resources for caregivers, such as training and webinars, and often focused on providing quality care to the care recipient. Information also included how to cope with stressors, strategies to use in caregiving, and tips on communicating with healthcare professionals.

2. Support to access services

Support to access services included resource databases, links to resources, and consultations. For example, L'appui Pour Les Proches Aidants in Quebec is a consultation, information, and referral service (resource directory).

3. Social and peer support

Examples of social/peer supports included online peer support groups, one-to-one peer supports, and safe online spaces to share experiences.

4. Respite

Respite services to caregivers include overnight care (up to 14 days) as well as social engagement services. While some respite services have an associated cost, some are free.

5. Advocacy

Advocacy support included encouraging governments to recognize unpaid caregivers and provide accessible supports.

6. 24/7 Helpline

Helpline services connected caregivers to local supports. Examples include the 24-hour Ontario Caregiving Organization helpline.

7. Financial support

Financial supports included federal and provincial government tax credits. No programs offered direct financial support to unpaid caregivers.

Types of support offered

Information is the most offered support

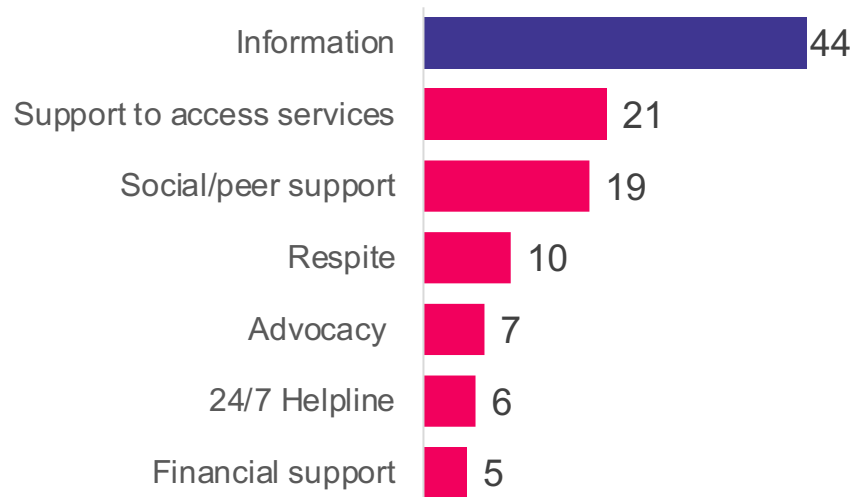
Across all organizations scanned (n=56):

- **Educational information and tips for caregiving** (n=43, 77%) was the most common type of support offered
- **Support to access services** was the second most common types of support offered (n=21, 38%),
- **Social/peer support** services was the third (n=19, 34%).
- The least common type of support in place was financial support (n=5, 9%) highlighting a potential gap in this area.

Many organizations offered more than one type of support

- To be included in the scan, each organization offered at least one of the types of support, but many organizations (n=33, 59%) offered two or more types of support.
- Figure 5 summarizes the types of support offered.

Figure 5. Types of support offered across 56 organizations



“We advocate for recognition and support for the family, friends and neighbours whose unpaid care is the hidden backbone of Ontario’s health system” -
Ontario Caregiver Coalition

Caregivers have diverse needs

The scan revealed programs that catered to the needs of different groups of caregivers, emphasizing that caregivers have diverse backgrounds and may have different needs. Below we provide examples of some groups of caregivers who may need tailored supports.

Youth

Young carers include children or youth ages 5-18 in a caregiving role for a parent, grandparent, sibling or any relative. They face the challenge of balancing caregiving responsibilities with school, social life, and personal development. Examples of support include Hospice Toronto “Young Carers” program and Ontario Caregivers Organization “Young Caregivers”.

Indigenous caregivers

First Nations, Inuit, and Métis caregivers need access to respectful and culturally appropriate care for themselves and those they care for. While OCO has compiled a list of resources that may help caregivers from Indigenous communities, the scan revealed a lack of information on supports tailored to Indigenous caregivers

2SLGBTQIA+

According to the Ontario Caregiver Organization, as many as 250,000 caregivers across Canada care for, or are 2SLGBTQIA+ identified themselves. Members of the 2SLGBTQIA+ community may encounter unique challenges, such as discrimination in healthcare settings, and the need to advocate for inclusive and culturally competent care.

Older adults

Older adults, typically carers ages 55+, often deal with age-related health issues, which can make caregiving physically and emotionally demanding. They may also need to navigate the healthcare system for their own needs.

Remote communities

Caregivers living in remote or rural areas face the challenge of limited access to healthcare services and resources. They may need to travel long distances for medical appointments or support, which can be logistically and financially challenging. The scan did not identify any supports tailored to this group of caregivers.

Dual caregivers

Dual or Double Duty caregivers are individuals who provide care both at home and at work. They face the considerable challenge of balancing care responsibilities for two distinct groups.

Working caregivers

Many caregivers are working and provide unpaid care to someone. These caregivers, and their employers, benefit from workplace that are inclusive and accommodating to their needs.

Findings: One-on-one interviews

What we heard in the interviews

We conducted a total of 7 interviews (6 in English, 1 in French), with individuals from 6 organizations supporting caregivers who enable aging in place across Canada.

Organizations included national, provincial, and local providers, as well as two universities (McMaster and University of Alberta) conducting research and providing support in the area. While some organizations were relatively new to the field (e.g., Ontario Caregiver Organization was founded in 2019; Canadian Centre for Caregiving Excellence launched in 2022), others had been active in the field of caregiver support for many years (e.g., research spanning decades).

Organizations shared similar goals to improve the lives of caregivers. Caregivers included those who enable aging in place, and often extended to support *“everyone who is taking care of someone (18+) who has a loss of autonomy or ability to take care of themselves.”*

Organizations’ roles in providing caregiver support varied. Just as the organizations we interviewed were diverse, so were their roles in providing support to caregivers. For example, Ontario Caregivers Organization provides a 24/7 helpline, online resources, communications, and partnerships with primary care facilities;

- University of Alberta provides education to healthcare providers to support family caregivers;
- Baluchon Répit long terme in Quebec provides direct support through in-home respite care.

Organizations that provide services free of charge rely on funding, grants, and donations. Among those interviewed, organizations do not charge caregivers to access the services they offered. Organizations received funding through government funding, grants (e.g., United Way), and donations. Some interviewees emphasized the need for continuous government funding to continue to provide programming at no cost to care givers.

List of interviewee organizations

- Baluchon Répit long terme
- Canadian Centre for Caregiving Excellence
- Family Services Toronto
- McMaster University
- Ontario Caregivers Organization
- University of Alberta

“In our ideal world, the caregiver would be regarded as part of the care team and supported and empowered in their role across all transitions in the system.”

Examples of supports

In one-on-one interviews, we heard about a range of supports offered to caregivers. On this page, we list some of the key supports offered by organizations we interviewed.

University of Alberta

- Caregiver-Centered Care focusses on practical research about what family caregivers need and how healthcare providers can support family caregivers.
- Also offers educational courses for healthcare providers.
- <https://www.caregivercare.ca/research>

McMaster University

- Research on caregiving, funded by Canadian Institutes of Health Research (CIHR) and Social Sciences and Humanities Research Council of Canada (SSHRC) grants.
- Offers tools and resources on how to create carer-friendly workplaces.
- <https://ghw.mcmaster.ca/>

Canadian Centre for Caregiving Excellence

- Provides lists of caregiver resources across Canada
- Offers funding to caregiver support networks and Communities of Practice, including conferences
- Supports advocacy for caregivers
- Hosts Canadian Caregiving Summit
- <https://canadiancaregiving.org/>

Ontario Caregiving Organization

- 24-hour help line
- One-on-one peer support
- Supporting Caregiver Awareness, Learning and Empowerment
- Caregiver Coaching Program
- Online eLearning library
- Caregiver Mental Health & Well-Being and Addiction course
- Essential Care Partner (ECP) support hub
- Newsletters, toolkits, and webinars
- <https://ontariocaregiver.ca/>

Baluchon Répît long terme (Quebec)

- Offers in-home respite (4 to 14 days) to caregivers who want to keep their loved one who is not independent at home.
- <https://repertoire.lappui.org/fr/organisation/baluchon-repit-long-terme-a-domicile>

Family Services Toronto, Seniors and Caregivers Support Service

- Caring for Caregivers (an ongoing peer support group)
- <https://familyservicetoronto.org/our-services/programs-and-services/seniors-and-caregivers/>

Promising practices

Through the interviews, we heard about some of the most promising practices in supporting caregivers who enable aging in place. Organizations gathered evidence for these practices through a mix of qualitative and quantitative research. Promising practices include:

- ✓ **Offering a variety of supports** to meet individual needs, including offering virtual peer and counselling support.
- ✓ **Helping caregivers navigate available supports** to find the support they need.
- ✓ **Supporting caregivers' physical and mental well being needs**, including support when they feel overwhelmed or distressed.
- ✓ **Providing opportunities for caregivers to come together** to support each other.
- ✓ **Educating employers** on the importance of supporting carers in the workplace and how to create carer-friendly workplaces
- ✓ **Educating healthcare workers** on the importance of acknowledging caregivers and the important role they play as a member of the care team.



“Caregivers traditionally have been a rather neglected population because we tend to concentrate on the seniors at risk. Caregivers are a high-risk population and there is little understanding that caregivers come with a lot of caregiving burden and burnout, and they do not have an avenue to be able to speak or talk.”

Lessons learned

Through the interviews we heard some of the most important lessons learned about providing support to caregivers. Although specific needs vary by caregiver, **in general caregivers:**

- may not recognize or think of themselves as a caregiver, and may not know what supports are available to them
- can experience burden from trying to navigate the healthcare system
- benefit from support early in the process “before they reach burnout”
- need respite, mental health support, and peer support
- appreciate access to virtual peer and counselling supports
- require support as caregiving needs change (e.g., increasing level of support required)
- benefit from being acknowledged as part of the health care team; caregivers feel better supported when they know an organization or provider understands the challenges they face.

At the organizational level, we heard that organizations need dedicated resources, such as government funding, to maintain programs.



“Caregivers would like healthcare providers to support them and when they are supported it makes a huge difference to them. Essentially, we need to ask what help they need to care and complete a needs assessment tool like the one we use in homecare settings to help navigate the system.”

“Ensuring caregivers are really recognized and validated as part of the care team makes a big difference, not just as a proxy for the patient, but that their perspective is really heard.”

What's next?

Next steps

Examples of supports



Share key findings from this report to help spread awareness about existing supports for caregivers who enable aging in place across Canada

- e.g., share through team discussions, at conferences, and online



Build capacity to support caregivers who enable aging in place

- e.g., ensure caregiver support is incorporated into HEC tools and resources such as implementation templates, needs assessments, and asset mapping



Integrate the findings into HEC's Aging in Place program

- e.g., review suggestions in various HEC programs such as Nursing Home Without Walls

Appendices

Appendix A: Interview Guide

About the interview: Healthcare Excellence Canada has asked Cathexis to conduct an environmental scan along with these interviews to explore existing caregiver support programs. Our interview will focus on the programming your organization has in place and should take no more than 30 minutes.

Cathexis will share the findings with HEC in a final report . The HEC team will use the information with the intention of spreading and scaling promising practices.

Your privacy: With your permission, we will audio-record this interview for note taking purposes. We will only use notes and recordings for the purpose of this project.

Do I have your permission to record this interview? _____

Background

1. Tell me about your organization and your role.
 - a. How long has your organization been offering caregiver support programs?
 - b. How do these programs fit into your organization's goals?

About the program(s)

1. Could you describe the caregiver support program or programs that your organization currently offers? [Interviewer may have some background information on programs from the environmental scan]
 - a. What issues do these programs aim to address?
 - b. Is there a fee for these programs? [We are interested in programs or practices that fit within governmental programs]
2. Who is the target audience for the programs? Who typically participates?
 - a. How do you promote your programs and reach to your target audience?
3. Do you collaborate with other organizations or agencies to implement your programs?
 - a. How do these partnerships affect your programs?

Promising Practices

1. Could you share a few success stories or examples of caregivers that have benefited from your programs?
 - a. Are there any other ways your organization measures the success or impact of your programs?
2. What lessons have you learned from your program experiences about implementing caregiver support programs?

Appendix B: Organizations by focus

Organizations with programs for general caregivers (n=33)

Alberta Health Services
Archdiocese of Toronto
Bayshore Healthcare
Canadian Centre for Caregiving Excellence
Canadian Mental Health Association Toronto
Caregiver Connections
Caregiver Exchange
Caregivers Alberta
Caregivers Nova Scotia
Caregiving Matters
Doctors of BC
Éducaloi
Family Caregivers of BC
Fondation Maison Gilles-Carle
Government of BC - Caring for the Caregiver
Government of Canada
Government of Manitoba
Government of Nunavut
Government of Prince Edward Island
Government of Quebec
Government of Yukon
Holland College / Government of PEI
L'APPUI POUR LES PROCHES AIDANTS
McMaster
RANQ
Saskatoon Council on Aging
Team CarePal app
The Caregiver Space
University of Alberta
Von Live Every Day
Rainbow Caregivers Network
Woodgreen
Young Carers Program

Organizations with programs for unpaid caregivers that support aging in place (n=23)

AGEWELL
Alzheimer's Society (Peel)
Association des proches aidants de la Capitale-Nationale + The Wellness Centre
Baluchon Répit long terme
Canadian Home Care Association
Canadian Virtual Hospice
CarePartners
Caring 4 Carers
Family Service Toronto
Forward with Dementia
Government of Canada - Veteran's Affairs
Government of New Brunswick
Government of Northwest Territories
Hospice Palliative Care Ontario
Links2Care
NorQuest College
Nucleus Independent Living
Ontario Caregiver Coalition
Ontario Caregiver Organization
Provincial Geriatrics Leadership Ontario (PGLO)
Revenue Quebec
Saint Elizabeth Health
Seniors Newfoundland

Appendix C: Organizations by geographic location

Alberta (n=5)

- Alberta Health Services
- Caregivers Alberta
- Caregiver Connections
- NorQuest College
- University of Alberta

British Columbia (n=3)

- Doctors of BC
- Family Caregivers of BC
- Government of BC - Caring for the Caregiver

Manitoba (n=2)

- Canadian Virtual Hospice
- Government of Manitoba

Newfoundland (n=1)

- Seniors Newfoundland

Northwest Territories (n=1)

- Government of Northwest Territories

Nova Scotia (n=1)

- Caregivers Nova Scotia

Nunavut (n=1)

- Government of Nunavut

Ontario (n=18 including 2 regional websites searched)

- Alzheimer's Society Peel
- Archdiocese of Toronto
- Bayshore Healthcare
- Canadian Mental Health Association Toronto
- Caregiver Exchange
- CarePartners
- Caring 4 Carers
- Family Service Toronto
- Hospice Palliative Care Ontario
- Links2Care
- McMaster
- Nucleus Independent Living
- Ontario Caregiver Coalition
- Ontario Caregiver Organization
- Provincial Geriatrics Leadership Ontario (PGLO)
- Rainbow Caregivers Network
- Woodgreen
- Young Carers Program

Prince Edward Island (n=2)

- Government of Prince Edward Island
- Holland College / Government of PEI

Quebec (n=8)

- Association des proches aidants de la Capitale-Nationale + The Wellness Centre
- Baluchon Répit long terme
- Éducaloi
- Fondation Maison Gilles-Carle
- Government of Quebec
- L'APPUI POUR LES PROCHES AIDANTS
- RANQ
- Revenue Quebec

National Organizations

– provide services across multiple provinces (n=11)

- AgeWell
- Canadian Centre for Caregiving Excellence
- Canadian Home Care Association
- Caregiving Matters
- Forward with Dementia
- Government of Canada
- Government of Canada - Veteran's Affairs
- Saint Elizabeth Health
- Team CarePal app
- The Caregiver Space
- Von Live Every Day