

ADVANCING COLLECTIVE **PRIORITIES** A CANADIAN

CARER STRATEGY







The report was compiled through web searches and input from subject matter experts; it is not intended to be an exhaustive listing of all carers supports. Resource links and websites are provided for readers to access more information.

All efforts were made to ensure the accuracy of the information as of April 2017.

This report is presented by:

CANADIAN CANCER ACTION NETWORK*

A national incorporated membership organization dedicated to ensuring patient interests remain a key priority on the national cancer agenda. CCAN was created in order to ensure that the patient and caregiver perspective is and remains firmly embedded in work across the cancer control continuum.

CANADIAN HOME CARE ASSOCIATION

A national not-for-profit membership association representing home care stakeholders from governments, health authorities, publically funded home care programs, service providers, medical and technology companies, researchers, and others with an interest in home care. The Canadian Home Care Association advances excellence in home care through leadership, awareness, advocacy and knowledge.

CARERS CANADA

An alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of carers in Canada. Carers Canada's mission is to enhance the quality of life for carers through synergistic partnerships and global advocacy that strengthens and honors the voice of carers.

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FOREWORD

Across the country, millions of Canadians take on an unpaid caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. While providing care for loved ones, friends and neighbours is not a new concept, today's context of caring is very different. Social and economic conditions have changed significantly. The family unit is growing smaller, more diverse and dispersed. Employment opportunities and expectations are changing, with more women entering the workforce and more individuals delaying retirement. At the same time, the factors driving change to our health care system are undeniable and mounting. An aging population, increasing in life expectancy, rise in chronic and life limiting illness and shortages in health human resources are shifting care from institutions to care within the home. In light of these socio-economic changes, carers are stepping up to provide care and fill the gap in our publicly funded health care system. For many carers, this can mean juggling their work, personal and caring responsibilities, often at the cost of their emotional, physical and financial status.

To this end, we began our collaboration in 2013 through the *Mobilizing Action: Family Caregivers in Canada* project to bring cohesion to pan-Canadian efforts and accelerate actions that will enhance the well-being of Canadian carers. We are pleased to see the great strides that have been made on developing legislation, policy and programs to better meet the needs of carers. This report has been developed to showcase the progress made and outline the policies and practice initiatives that support carers across the country. The report was compiled through web searches and input from subject matter experts; it is not intended to be an exhaustive listing of all carers supports. Resource links and websites are provided for readers to access more information.

Through this report, we aim to further identify opportunities for broader pan-Canadian collaboration and build on each other's efforts to achieve measurable outcomes and values for patients, carers and our society as a whole. In doing so, we hope to continue the momentum in creating the necessary changes for a compassionate and caring society, one that fully recognizes and respects the valuable role of carers.

Kindest regards,

Nadine Henningsen President, Carers Canada

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Who is a

Also referred to as caregiver or family caregiver, carer is a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness.



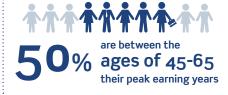
labour force





Carers provide **/ hours** of help to family and friends for every 2 hours of professional home care





CARERS MAKE A DIFFERENCE

Contribute \$

in unpaid labour to our health care system



More than 2 million Canadians can live safely in their homes because

of the support of carers







Providing wide array of activities:



Personal and medical care



Housekeeping

Advocate



Financial management



Social/emotional support

Sustainability of the labour market

billion

in saving from a loss of productivity through their continued participation

HOW CARING IMPACTS CARERS' LIVES

WORK

44% miss days of work

15% reduce work hours

10% leave the labour force (quit, fired or retired early)

FINANCES

Carers spend

\$100 to

300/month

on expenses directly related to caring

HEALTH & WELL-BEING

Carers can experience an array of negative emotional and health outcomes



[·] Fast, J., Keating, N., Lero, D., Eales, J., & Duncan, K. 2013. The Economic Costs of Care to Family/Friend Caregivers: A Synthesis of Findings. UAlberta: RAPP.

[·] Hollander, J. M., Liu, G., & Chappell, N. 2009. Who Cares and How Much. Healthcare Quarterly, 12(2), 42-49.

Research on Aging, Policies, and Practice. 2014. Combining Care Work and Paid Work: Is it Sustainable?

[·] Statistics Canada. 2013. Portrait of Caregivers.

[·] Statistics Canada. 2014. Receiving Care at Home.

A CANADIAN CARER STRATEGY

"IT'S NOT IF, IT'S WHEN YOU WILL BE A FAMILY CAREGIVER"

Nadine Henningsen, President, Carers Canada

arers come from different backgrounds, age demographics and income levels; there is no one-size-fits-all solution. Despite this diversity, during consultations with carers and caregiver support groups across the country, Carers Canada identified a number of common needs required to effectively support carers. These universal priorities were incorporated into *A Canadian Carer Strategy*, launched in 2008 and updated in 2014 following a series of consultations across Canada to ensure the Strategy remains an accurate representation of the needs of carers.

The Strategy provides a framework for the development of legislation, policy and programs that support the vital role of carers. It serves as an anchor for collaborative action and commitment between diverse stakeholders to achieve the vision of "A Canada that recognizes, respects and supports the integral role of carers in society." The five essential elements of the strategy include:

SAFEGUARD THE HEALTH AND WELL-BEING OF CARERS.

2

MINIMIZE EXCESSIVE FINANCIAL BURDEN PLACED ON FAMILY CARERS.

3

IMPROVE ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES.



CREATE SUPPORTIVE WORKPLACE AND EDUCATIONAL ENVIRONMENTS THAT RESPECT CAREGIVING OBLIGATIONS.

5

INVEST IN RESEARCH ON CARERS AS A FOUNDATION FOR EVIDENCE-INFORMED DECISION MAKING.

NATIONAL SUPPORTS

SAFEGUARD HEALTH AND WELL-BEING

- The Federal/Provincial/Territorial Ministers Responsible for Seniors are raising awareness around 'Caregiver Readiness' by engaging current and future Canadian carers to start a *care conversation* and *care planning* as early as possible, before an emergency happens.
- The <u>Veteran Independence Program</u> offers financial assistance to qualified primary caregivers under the Veterans Health Care Regulations to obtain services such as housekeeping and/or grounds maintenance; personal care, access to nutrition, health and support services.
- All Things Caregiving: <u>Elizz</u> provides support to Canadian caregivers through combination of caregiver services and resources, in-home care support and virtual health.

MINIMIZE FINANCIAL BURDEN

- The Caregiving Recognition Benefit, which is replacing the Family Caregiver Benefit, provides a non-taxable \$1,000 monthly benefit payable directly to caregivers for ill and injured veterans.
- Canada Caregiver Credit (replacing the Caregiver Credit, Infirm Dependant Credit and Family Caregiver Tax Credit) is a non-refundable credit for those providing care to dependent spouse/common law partners, minor child or relatives with infirmities or disabilities, regardless of if they live together.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- <u>Canadian Armed Forces</u>' <u>Member Assistance program</u> helps members of the Armed Forces and family members who have personal concerns that affect their personal well-being and/or work performance to talk to a professional counsellor.
- <u>Canadian Armed Forces Connection's Caregiver Web page</u> outlines financial benefits and resources for caregivers of the Canadian Armed Forces members and families with special needs children.
- •An online directory, <u>Family Navigator</u>, connects Canadian forces families with local resources, tools and information to support a child with special needs, person with a disability, an elderly parent who requires extra support, or a Canadian Forces Member with an operational injury.
- <u>Military Family Resource Centre's Family Information Line</u> is a referral, crisis management and supportive counselling services to provide support and guidance for veterans and their families.
- The Alzheimer Society provides information, support and education for caregivers of those with Alzheimer's disease and other dementias across Canada. Call 1-800-616-8816 or contact the local Alzheimer Society to access information and support.
- Tyze Online Personal Network is a platform to help carers create strong, supportive and private networks online.



- The Children's Oncology Group provides a comprehensive resource for children and their families, including information on diseases, side effects and a Family Handbook.
- Cancer Chat Canada provides
 free and professionally-led online
 support groups for Canadians
 affected by cancer, including
 patients, survivors and family
 members. Support groups are
 structured to provide emotional
 support and a place to safely
 discuss personal topics.
- Cancerview.ca, supported by the Canadian Partnership Against Cancer, connects Canadians to online services, information and resources in cancer prevention, screening, treatment, and supportive, palliative and end-oflife care.

- <u>Kids Help Phone</u> is Canada's only national 24-hour, bilingual and anonymous phone counselling, web counselling and referral service for children and youth.
- <u>LivingMyCulture.ca</u>, <u>MyGrief.ca</u> and <u>Methadone4Pain.ca</u> are knowledge tools developed by the Canadian Virtual Hospice, through the support of the Canadian Partnership Against Cancer's Palliative and End-of-Life Care projects, to inform and empower patients, caregivers and educate health care providers.

SUPPORTIVE WORKPLACE ENVIRONMENT

- Employment Insurance Special Benefits:
 - The <u>Compassionate Care Benefit</u> is paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months).
 - Special benefits for Parents of Critically Ill Children are available for up to a maximum of 35 weeks for parents who have to be absent from work to provide care or support their critically ill or injured child.
 - Starting 2017-18, a new caregiving benefit of up to 15 weeks is available to help eligible Canadians caring for an adult family member who requires significant support in order to recover from a critical illness or injury.
- An amendment of the Canada Labour Code ensures federally regulated employees have the job protection they need while they are receiving caregiving benefits and the right to request more flexible work arrangements.
- The Federal/Provincial/Territorial Ministers Responsible for Seniors released Tips for Employed Caregivers of Family or Friends and Tips for Employers, Helping Employees Balance Work and Caregiving Responsibilities.
- •A Guide to Balancing Work and Caregiving Obligations. Human rights law prohibits discrimination based on the ground of family status. This means that when an employee must care for a family member, employers have a legal obligation to accommodate that employee. This guide provides tips for developing accommodation solutions that are in harmony with human rights law. It outlines the rights and responsibilities of the employee, the employer, unions and/or employee representatives.

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

- The Caregiver Network is Canada's largest online learning network supporting family caregivers, their loved ones and the health care professionals who work on their behalf.
- Dr. Allison Williams (CIHR Institute for Gender and Health Chair in Gender, Work and Health, McMaster University) in partnership with the Canadian Standards Association is developing a Canadian Caregiver-Friendly Workplace Standard.
- Through publications, research initiatives, presentations and social media, the Vanier Institute of the Family works to enhance the national understanding of how families interact with, have an impact on and are affected by social, economic, environmental and cultural forces.



The Canadian Cancer Society offers a wide range of support and information for people with cancer and their family, friends and caregivers:

- Cancer Information Service
 provides answers to questions
 about all types of cancer,
 diagnostic tests, treatments,
 side effects, clinical trials and
 many other cancer-related
 topics.
- Peer Support Service connects people living with cancer and caregivers with trained volunteers who offer encouragement and share ideas for coping all from their unique perspective as someone who's been there.
- Online community –
 CancerConnection.ca –helps
 people who have cancer, cancer
 survivors and caregivers share
 their experiences and build
 supportive relationships.
- Community Services Locator a searchable database of over 4000 cancer-related services and resources nationwide or at one of their community offices across the country to find more cancer-related services in the area.

BRITISH COLUMBIA

SAFEGUARD HEALTH AND WELL-BEING

- The Government of British Columbia offers resources to support caregivers.

 This includes information on self-care, respite and community support.
- The BC Medical Association known as "Doctors of BC" has developed a physician toolkit to help physicians support carers and involve them as partners in care.
- The Better at Home Program helps seniors with daily tasks so they can continue to live independently in their homes and remain connected with their communities.
- The First Nations Health Authority's Home and Community Care offers extensive home care services and in-home respite for First Nations peoples in need.

MINIMIZE FINANCIAL BURDEN

- Choice in Supports for Independent Living allows clients to receive funds from their local health authority to purchase their own home support services.
- The <u>At Home Program</u> offers respite and medical benefits to assist parents or guardians with some of the extraordinary costs of caring for a child with severe disabilities at home.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- The Government of British Columbia offers training and role management tools, daily care tips and care guide resources.
- Family Caregivers of British Columbia (formerly called Family Caregivers' Network Society), in partnership with the Ministry of Health, offers the Caregiver Support Line, education for caregivers and health professionals and an online caregiver resource centre.
- <u>HealthLink BC</u> provides access to non-emergency health information and advice by telephone, a website, a mobile app, and a collection of print resources.
- HeretoHelp by the BC Partners for Mental Health Information offers toolkits and workbooks designed to assist families in caring for a family member with a mental illness with information, caregiving planning and practical resources.

SUPPORTIVE WORKPLACE ENVIRONMENT

 Various job-protected employment leaves are available under the BC Employment Standard Act, 2015 including Compassionate Care Leave (up to 8 weeks unpaid), Family Responsibility Leave (up to 5 days unpaid) and Bereavement Leave (up to 3 days unpaid).

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

• The Family Caregivers of British Columbia is partnering with the BC Ministry of Health's Patients as Partners initiative on its <u>Caregiver Engagement Program</u> to expand support for family caregivers and to ensure their voice is included in health system improvement efforts.



The BC Cancer Agency's Art
Therapy Family Program, the
'Anything-But-Ordinary Journey',
is a safe, online environment
created to help children who
have a family member with
cancer to explore their feelings,
and to help parents support
their children as they work
their way through questions,
emotions and understanding
of this journey the entire family
is on.

ALBERTA

SAFEGUARD HEALTH AND WELL-BEING

- <u>Caregivers Alberta</u> increases communities' capacity to better support caregivers by educating professionals, promoting networking and sharing of best practices through their Caregiver Support Team and Caregiver Navigator programs.
- The Special Needs Assistance for Seniors Program, offered by the Government of Alberta, provides a funding for up to four weeks of respite care to an eligible low-income senior who lives with a family caregiver who provides daily care to the senior.
- The AHS Indigenous Health Program advocates for and facilitates support of Indigenous patients and their families across the continuum of care.

MINIMIZE FINANCIAL BURDEN

• The Persons with Developmental Disabilities (PDD) program provides support to families, including caregivers, through the Family Managed Services option. The PDD program can pay for extended family members to be caregivers.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- The AHS Family Caregiver Centre in Calgary offers counselling, education programs and referrals to health care and community services.
- Alberta's Mental Health Help Line provides crisis intervention, information and referral to mental health programs and other agencies where appropriate.
- The Alberta Caregiver College®, developed by Alberta Health Services and the Glenrose Rehabilitation Hospital, offers a range of courses and tools to enhance caregivers' capacity in caring for their family members.
- Caregivers Alberta offers group and one-on-one supports to help caregivers connect with others, navigate the system and look after themselves while providing care through COMPASS for the Caregiver, Caregiver Advisor, Caregiver Information Sessions and Community Caregiver Groups.
- Health Link Alberta provides 24/7 nurse telephone advice to provide crisis intervention, information and referral.

SUPPORTIVE WORKPLACE ENVIRONMENT

• Under Alberta's Employment Standards Code – Compassionate Care Leave, eligible employees who leave work to become a caregiver for a gravely ill family member are entitled to up to eight weeks of unpaid, job-protected leave of absence.

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

• Through an Age-Well Catalyst Grant, Dr. Janet Fast (University of Alberta) is leading the Connecting Working Caregivers Catalyst Project, to gain a better understanding of employers' and caregiver-employees' current experiences with, and beliefs about, the ability of assistive technologies to help them integrate, manage or balance their paid work and care responsibilities, and reduce care-related human resource management challenges.



Alberta Health Services offers specially trained nurses in all 15 community cancer facilities across the province to be cancer patient navigators, who help guide patients and their families through their treatment, follow up care and beyond.

SASKATCHEWAN

SAFEGUARD HEALTH AND WELL-BEING

- The Community Living Service Delivery offers a <u>Family Respite Program</u> to provide parents and guardians of children with intellectual disability a temporary or short-term break from the daily responsibilities of caregiving.
- The Saskatoon Health Region Client Patient Access Service provides access to and determines eligibility to <u>Community Day Programs</u> and <u>Special Care Homes</u> services, which include respite care.

MINIMIZE FINANCIAL BURDEN

- <u>Individualized funding for home care</u> offers direct funding for those who wish to manage their own support services in home.
- The Saskatchewan Assured Income for Disability is an income support program for people with significant and enduring disabilities.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- <u>Saskatoon Caregiver Information and Support</u>, a program of the Saskatoon Council on Aging, provides support group and one-on-one professional caregiver counselling over the phone or in office, as well as caregiver resource guides.
- Developed in partnership with the Saskatoon Public Library, Saskatoon Health Region and the City of Saskatoon, The Saskatoon Council on Aging has launched an <u>electronic resource hub</u> as a one-stop information source for older adults, their caregivers and service providers.
- The Alzheimer Society of Saskatchewan offers First Link and Caregiver Support Groups to connect carers with information, support and services.

SUPPORTIVE WORKPLACE ENVIRONMENT

• The <u>Saskatchewan Employment Act</u> provides various job-protected employment leaves to employees who are caregivers, which includes <u>Compassionate Care</u> <u>Leave</u> (up to 28 weeks unpaid), <u>Critically-Ill Child Care Leave</u> (up to 37 weeks unpaid) and <u>Bereavement Leave</u> (up to 5 days unpaid).

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

• The <u>Rural Dementia Action Research (RaDAR) Team</u> an interdisciplinary group of knowledge users and researchers from three Canadian provinces (SK, AB, ON) and the United Kingdom, are undertaking several research projects to improve primary health care delivery to people with mild cognitive impairment and dementia and their caregivers in rural and remote communities.



- Social Workers at the Saskatoon Cancer Centre are available to help patients and families cope with the physical and emotional impact of cancer through a variety of supportive services, such as assessment and consultation, patient navigation assistance, emotional support, family counseling, relaxation training, palliative and bereavement counseling.
- The Patient and Family Resource
 Centres at the Saskatoon
 Cancer Centre and the Allan
 Blair Cancer Centre support
 patients and families by
 providing current and relevant
 information about specific types
 of cancer, self-help, nutrition
 and a variety of other topics.

MANITOBA

SAFEGUARD HEALTH AND WELL-BEING

- The Manitoba Caregiver Recognition Act sets out principles and actions for government and non-government agencies to support caregivers.
- The first Tuesday in April is a legislated Caregiver Recognition Day in Manitoba, under the Caregiver Recognition Act.
- The <u>Manitoba Caregiver Coalition</u> joins caregivers, service providers, policy makers and other stakeholders to identify and respond to the needs of caregivers in Manitoba.
- The <u>careAware Campaign</u> aims to raise awareness in support of Manitoban caregivers and to provide venues for caregivers and others to learn more about programs and services available in Manitoba.
- Caregiving with Confidence (formerly Rupert's Land Caregiver Services) offers a range of support services for family caregivers of persons 55+.

MINIMIZE FINANCIAL BURDEN

• Manitoba's Primary Caregiver Tax Credit provides a refundable credit of up to \$1400/year to people who act as a primary caregivers for spouses, relatives, neighbours or friends who live at home in Manitoba.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- The Manitoba Seniors and Healthy Aging Secretariat's <u>Information on Caregiving</u> portal contains caregiver resources and published guidelines, such as <u>Inventory</u> for Caregivers in Manitoba and A guide for the Caregivers.
- The Senior Information Line, 1-800-665-6565, provides information and referrals about caregiving and other senior-related concerns.
- The <u>Pinaymootang First Nation Health Centre</u>'s Niniijaanis Nide Program (My Child, My Heart) is a coordinated and integrated program for children with complex care needs and their families, living on-reserve in Manitoba's Interlake Region.

SUPPORTIVE WORKPLACE ENVIRONMENT

- careAware Workplaces aims to recognize organizations and businesses that support their employees who provide care to a friend or family member.
- Manitoba's Employment Standard Code provides up to 8 weeks unpaid <u>Compassionate Care Leave</u>, up to 3 days unpaid <u>Family Leave</u> and up to 3 days unpaid Bereavement Leave.

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

• The <u>Caregiver Advisory Council</u> provides the Minister of Health, Seniors and Active Living with information, advice and recommendations to promote awareness of and support for caregivers. The Committee meets regularly to review the latest research and identify potential solutions to current issues, including system navigation, access to information and communication between caregivers and health care professionals.



- Cancer Care Manitoba's Patient and Family Support Services has skilled professionals to support patients and their family through the emotional and practical challenges related to the cancer. Services provided include counselling, spiritual health services, support groups, and Patient and Family Resource Centre.
- The Community Cancer Programs
 Network is an innovative program
 by CancerCare Manitoba that
 works in partnership with the
 Regional Health Authorities
 to enable rural and northern
 Manitobans to receive their
 cancer care closer to home.

ONTARIO

SAFEGUARD HEALTH AND WELL-BEING

- The Home and Community Care Services Act, 1994 identifies caregiver support services under the provision of community support services.
- Bill 66, Family Caregiver Day Act, 2016, if passed, will proclaim the first Tuesday in April as Family Caregiver Day.
- Ontario invested an additional \$20 million in 2017 for respite care, bringing its three-year commitment to \$120 million.
- The Ontario Caregiver Coalition provides a strong advocacy presence in Ontario and ensures involvement of caregivers on many government advisory bodies, focusing on awareness, respite services and financial compensations.
- The Powerhouse Project Young Carers Initiative offers a variety of free services and activities to empower young carers and their families.

MINIMIZE FINANCIAL BURDEN

- Passport provides funding for services to support adults 18 years or older with a developmental disability and provide temporary relief for their caregivers.
- In its Budget 2017, Ontario simplifies the provincial caregiver and infirm dependent tax credits with a new non-refundable Ontario Caregiver Tax Credit of up to \$4,794.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- Patients First: A Roadmap to Strengthen Home and Community Care outlines the Ontario government's three-year plan to improve and expand home and community care, including enhancement of caregiver supports.
- Respiteservices.com provides information and facilitates access to local respite services across 38 Ontario communities.
- The Change Foundation provides a collection of research articles and websites on policy issues affecting caregivers through their Caregiver Resource Hub.
- Ontario's Dementia Strategy will provide more than \$100 million over three years to support people with dementia and those who care for them through better coordinated and enhanced services.

SUPPORTIVE WORKPLACE ENVIRONMENT

Ontario offers unpaid, job-protected leave for the following: Family Caregiver
 Leave (up to 8 weeks), Family Medical Leave (up to 8 weeks), Critically ill
 Childcare Leave (up to 37 weeks) and Personal Emergency Leave (up to 10 days).

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

• The Change Foundation is investing \$9 million over three years into four Changing CARE community partnerships across Ontario poised to enhance the experience family caregivers have with Ontario's health care system.



- Cancer Care Ontario formed

 Patient and Family Advisor
 Council to provide direct input into policies, programs, and practices based on patient, family member and caregiver experience.
- Commonly referred to as
 the Interactive Symptom
 Assessment and Collection
 (ISAAC) tool, Your Symptoms
 Matter allows patients and their caregivers assess and track
 their cancer related symptoms
 online. This tool makes it
 easier for healthcare providers
 to monitor changes in their
 patients' symptoms and identify
 those in need of care.

QUÉBEC

SAFEGUARD HEALTH AND WELL-BEING

- The home care support services in Québec include respite and psychosocial services for caregivers through the local community service centres (CLSCs) or health and social services centres (CSSSs).
- Regroupement des aidants naturels du Québec (RANQ) brings together local and regional associations, groups and organizations to raise public awareness and improve the quality of life of caregivers in Québec.

MINIMIZE FINANCIAL BURDEN

- The <u>Tax Credit for Caregivers</u> offers a refundable tax credit for each eligible care recipient residing with the caregivers.
- Respite Tax Credit is a refundable tax credit of up to \$1,560 per year for expenses incurred to obtain specialized respite services.
- The Financial Assistance Program for Domestic Help Services enables people using the services of a domestic help social economy business to benefit from a reduction of the hourly rate charged.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- Several services for caregivers are available through home care support services provisioned by Centre local des services communautaeries (CLSC, local community service centre) in Québec.
- The 17 regional <u>L'Appui Pour les proches aidants d'aînés</u> offices across Québec provides consultation, information and referral services through its online resource directory and caregiver support helpline.
- MeSSAGES, an online seven-week training program, provides caregivers with stress management tools to better prepare them in their role.
- <u>Aidants.ca</u> offers information, support and training resources to help caregivers take care of others, as well as themselves.
- <u>AMI- Québec</u> helps families manage the effects of mental illness through support groups, education, counselling and advocacy.

SUPPORTIVE WORKPLACE ENVIRONMENT

• Québec offers several job-protected leaves for family or parental obligations related to: death or funeral (up to 5 days, first day with pay), state of health (up to 10 days unpaid), and serious illness (up to 12 weeks unpaid; may be extended up to 104 weeks if the employee's minor child has a serious illness).

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

• The En route avec le Trousseau action research project aims to recognize and share the knowledge and expertise of caregiving groups and caregivers in Québec. The project resulted in a "Toolbox" to facilitate organizations in creating collective actions that will better support caregivers.



The Québec Cancer Foundation supports people with cancer and their loved ones in Québec through services suited to their needs and daily concerns. Services offered include:

- Information Support (Info-Cancer Hot Line and Library)
- Physical Wellness Program
- Psychological Support (telephone-peer matching, art therapy and support groups)
- Corporate Support Program

NEW BRUNSWICK

SAFEGUARD HEALTH AND WELL-BEING

- <u>Day Activity Services</u> for seniors, offered through the Social Development Regional Offices, provide caregiver relief, social support and meaningful social/ recreational activities in a group setting.
- The New Brunswick Extra- Mural Program and Long-Term Care Services

 Program connects client and their family with the community resources
 necessary to continue living at home, including respite support.
- The New Brunswick Department of Social Development offers a <u>Caregivers</u> Guide: Practical Information for Caregivers of Older Adults.
- The <u>Home First Strategy</u> outlines innovative approaches and initiatives to better serve the needs of New Brunswick's aging population, including support for caregivers.



• To assist low-income seniors in New Brunswick, the government offers an annual benefit of \$400 to eligible seniors.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- The <u>Seniors' Information Centre</u> is an online portal where 50+ adults, their families and caregivers can find resources and navigate through various community resources, public services and programs.
- Seniors Navigator, 1-855-550-0552, provides one-on-one assistance for seniors and their caregivers in navigating through government programs and services.
- Tele-Care, 811, is a 24/7 free confidential health advice and information line from registered nurses.

SUPPORTIVE WORKPLACE ENVIRONMENT

• Employment Standard Leaves in New Brunswick include Family Responsibility Leave for up to 3 days, Compassionate Care Leave for up to 8 weeks, Bereavement Leave for up to 5 days and Critical Illness Leave of up to 37 weeks unpaid.

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

- New Brunswick's Wellness Strategy 2014-2021 provides a framework that includes identifying, sharing and celebrating the strengths of family members to support positive change.
- We are all in this together: An Aging Strategy for New Brunswick includes a strategy to improve education and training opportunities for paid and unpaid caregivers. Specifically, actions to identify and communicate best practices related to respite options, First Nation's engagement and intergenerational opportunities.



New Brunswick pediatric oncology patients and their families have access to Pediatric Oncology Patient Navigators through Horizon Health Network or Vitalité Health Network from day one of the diagnosis. Navigators help families access the services they need and provide information on how to get the appropriate care for their children.

PRINCE EDWARD ISLAND

SAFEGUARD HEALTH AND WELL-BEING

- Health PEI and the PEI Organized Stroke Care Model published a Caregiver Handbook.
- The PEI Disability Support Program offers support planning assistance, family support programs and respite care.
- Based on assessed need and eligibility, in-home respite for the 24 hour caregiver and adult day program services are available through the PEI Home Care and Palliative Care programs. The Kingston Caregiver Stress Scale is a tool available to staff to assess caregiver stress.

MINIMIZE FINANCIAL BURDEN

- Family Health Benefit Drug Program helps low income families cover the cost of approved prescription medications.
- PEI offers social assistance for those who are unable to meet their basic needs.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- The Alzheimer Society of PEI offers support group, counselling and guides to support caregivers of individuals with Alzheimer's and dementia.
- The Prince Edward Island Seniors' Guide includes information about programs and services provided by the federal and provincial governments, community organizations and service providers.
- The Island Helpline, 1-800-218-2885, provides free, confidential emotional and crisis support to Islanders of all ages.

SUPPORTIVE WORKPLACE ENVIRONMENT

 PEI Employment Standards Act protects up to eight weeks of unpaid Compassionate Care Leave; one day paid and up to two days unpaid Bereavement Leave; three days of unpaid Family Leave; and up to thirty-seven weeks of unpaid Leave for Care of a Critically Ill Child.



- Caregivers have been included in the PEI Cancer Strategy in a number of ways, from information sharing, treatment planning, advance care planning and grief support. Family members also act as advisors on a number of cancer care committees.
- The PEI Cancer Treatment Centre, at the Queen Elizabeth Hospital and the Prince County Hospital Satellite Clinic, offers a personcentred approach to care and treatment. Services available include Cancer Patient Navigation Program and access to Social Workers and Spiritual Care Workers for emotional/financial/spiritual support.

NOVA SCOTIA

SAFEGUARD HEALTH AND WELL-BEING

- Respite care at home or in a Long Term Care facility is available through Continuing Care Programs and Services.
- The Independent Living Support (ILS) Program provides up to 21 hours a week supports and service to eligible individuals who are semi-independent and require minimum support in their own apartment or home.
- Direct Family Support for Children (DFSC) and Enhanced Family Support for Children (EFSC) provides funding for the purchase of respite services to assist with scheduled breaks for family caregivers of children with a disability.

MINIMIZE FINANCIAL BURDEN

- The Caregiver Benefit provides \$400 per month to caregivers of low income care recipients with a high level of disability or impairment. The program is open to First Nations individuals living on Reserve.
- <u>Supportive Care Program</u> provides \$500 per month to eligible Nova Scotians with cognitive impairment for Home Support Services (personal care, respite, meal preparation and household chores)
- The Self-Managed Care Program extends funds to eligible individuals with physical disabilities to hire their own care providers and develop their own care plans.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- <u>Caregivers of Nova Scotia</u> provides free programs, services, information and advocacy for unpaid, family and friend caregivers.
- The Caregiver's Handbook provides broad consumer understanding of topics related to caregiving, including useful tools, tips and resources for caregivers.
- Alzheimer's Society of Nova Scotia offers a network of Caregiver Support Groups and the Family Caregiver Education Series

SUPPORTIVE WORKPLACE ENVIRONMENT

• Employees can qualify for multiple unpaid job-protected leaves under the Nova Scotia's Labour Standard Codes: Compassionate Care Leave up to 28 weeks), Sick Leave (up to 3 days), Critically Ill Child Care Leave (up to 37 weeks), Bereavement Leave (up to 5 days).

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

- The <u>Nova Scotia Centre on Aging</u> undertakes research projects, continuing education initiatives and community engagement activities. Current projects include Financial Well-Being of Canadian Caregivers and Working CARERS Program.
- The Caregiver Assessment Project has received several peer reviewed grants and contracts to advance the practice of assessing the needs of family and friend caregivers (e.g. Evaluating the impact of caregiver assessment with older spousal caregivers of persons with cognitive impairment or commonly known as Timing of the C.A.R.E. Tool Project)



- Cancer Care Nova Scotia empowers patients and families to make informed decisions through:
 - Cancer Patient Navigators are trained oncology nurses that provide care, information and support in 9 communities in Nova Scotia.
 - List of publications and Patient
 Education Videos on a wide
 range of cancer related topics
 (ex. Coping with your Cancer,
 Cancer Care: A Guide for
 Patients, Families and
 Caregivers)
 - Living Beyond Cancer is a 3 hour class for people who have completed their cancer treatment and their families.
- Treatments and support for cancer patients and families are provided by the Nova Scotia Cancer Centre (Queen Elizabeth II Hospital in Halifax), Cape Breton Cancer Centre and IWK Health Centre for Women and Children. Support services include counselling, support groups, a resource library and education programs.
- The Atlantic Provinces Pediatric
 Hematology/Oncology Network
 (APPHON)'s website lists
 suggested links for patients and
 families seeking information about
 their oncology related issues.

NEWFOUNDLAND AND LABRADOR

SAFEGUARD HEALTH AND WELL-BEING

- The Eastern Health Respite Program is available at select personal care homes and nursing homes within the region, and may be booked for a maximum of 30 days per year.
- The Newfoundland and Labrador Home Support Program services include the provision of personal and behavioural supports, household management and respite at the minimum level.
- Saint Luke's Homes offers two days program, the <u>Adult Day Program and Respite Day Program</u>, to give caregivers a much-needed break from their caregiving role and attend to their personal needs.



• Newfoundland and Labrador's <u>Paid Family Caregiving Option Program</u>, a direct individualized funding model under the Provincial Home Support Program, provides subsidies for eligible seniors and adults with disabilities to pay a family member for approved home support.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- The Seniors Resource Centre in Newfoundland and Labrador offers a Caregiver Line.
- <u>Caregivers Out of Isolation</u> is an intergenerational program of the Seniors Resource Centre NL committed to supporting caregivers of all ages through information, education and recognition.

SUPPORTIVE WORKPLACE ENVIRONMENT

• Job-protected leaves under the Employment Standards in Newfoundland and Labrador include Compassionate Care Leave (up to 8 wees unpaid), Family Responsibility Leave (up to 7 days unpaid), Critical Illness of a Child Leave (up to 37 weeks unpaid) and Bereavement Leave (1 day off with pay and 2 days without pay)



The Cancer Care program of
Eastern Health offers emotional,
spiritual and bereavement
counselling. The patient
navigator, which are specially
trained oncology (cancer)
nurses, offers practical help
to bridge the gap and assist
patients, families and caregivers
understand and work through
the series of treatments,
services and challenges
encountered on their
cancer journey.

NUNAVUT

SAFEGUARD HEALTH AND WELL-BEING

- The Department of Health encourages healing within the home and offers support to Nunavummiut and their families during times of need. The Home and Community Program engages families in a person's care and offers respite care to support family members during illness.
- The Government of Nunavut aims to promote, protect and enhance the health and well-being of all Nunavummiut through its Healthy Living information portal.

MINIMIZE FINANCIAL BURDEN

- The Senior Citizen Supplementary Benefit is a monthly payment of \$200.00 made to low-income seniors in Nunavut.
- The Social Assistance Program is a program of last resort intended to help Nunavut families and individuals meet their basic needs when, for various reasons including disability, illness, low-income or periods of unemployment, they are unable to provide for themselves.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- Nunavut Kamatsiaqtut Help Line provides anonymous and confidential telephone counselling for northerners in crisis.
- The Wellness Drop in the Tukisigiarvik Centre offers practical support and assistance to Iqalummiut individuals and families with personal and family issues, health, healing, education and employment.

SUPPORTIVE WORKPLACE ENVIRONMENT

- Under the Nunavut Public Service Act, an eligible employee is entitled to be paid for authorized leave in the following circumstances:
 - Special Leave (up to 5 days for the death of an immediate family member; up to 5 days to care for immediate family members; 1 day at employee's discretion)
 - <u>Medical Travel Leave</u> (up to 4 days medical travel outside the home community required for the employee and/or his/her dependent to receive medical services).
 - Compassionate Care Leave offers up to 8 weeks of unpaid leave for caregivers.



Pauktuutit Inuit Women of
Canada is developing culturally
appropriate cancer awareness
tools and a toolkit to support
Inuit patients and caregivers,
as well as health care
professionals.

NORTHWEST TERRITORIES

SAFEGUARD HEALTH AND WELL-BEING

- The <u>Home and Community Care Program</u> provides short-term respite services and encourages the use of a Community Counseling Program to relieve caregiver burden or stress.
- The Government of the Northwest Territories Department of Health and Social Service released the <u>2015 NWT Caregivers Guide</u> to provide a practical resource for those caring for family, friends or neighbours.
- <u>Seniors' Information Handbook</u> outlines a comprehensive list of programs and services that seniors and their caregivers can access to help them make informed decisions so they can remain independent and active in their home communities.

MINIMIZE FINANCIAL BURDEN

- Income security programs in the NWT include the <u>Senior Citizen Supplementary</u> Benefit, Income Assistance Program and Senior Home Heating Subsidy.
- The Extended Health Benefits for Specified Disease Conditions provides assistance to eligible persons in the Northwest Territories who require health services beyond those covered by the Northwest Territories Health Care Plan.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- NWT Seniors Society informs seniors and elders about programs and services which can be of assistance to them, including the Seniors' Information Line.
- The Health and Social Services (HSS) System Navigator helps with questions and concerns about how to access services provided by the NWT health and social services system.
- The Government of the Northwest Territories sponsors the Métis Health Benefits program to provide registered Indigenous Métis residents of the Northwest Territories access to a range of benefits not covered by hospital and medical care insurance.

SUPPORTIVE WORKPLACE ENVIRONMENT

• The Employment Standards Act and Regulations protects up to 8 weeks unpaid Compassionate Care Leave and 3-7 days of Bereavement Leave depending on the location of the service.

INVEST IN RESEARCH AND KNOWLEDGE EXCHANGE

• The Department of Health and Social Services provides grants and contributions funding to help organizations in their efforts to look after the well-being of their residents and communities.



- Let's Talk About Cancer, an information portal by The Department of Health and Social Services, contains resources and tool kits relevant to NWT cancer patients, their loved ones and health care providers, as they navigate the cancer journey.
- "Believe in our Healing Journey: Supporting Continuity of Care for First Nations, Inuit and Métis Cancer Patients in the Northwest Territories" is a project funded by the Canadian Partnership Against Cancer to strengthen the NWT health system to support Aboriginal cancer patients and their families in a culturally safe way; increase knowledge among Aboriginal cancer patients and their families about the cancer journey; and identify ways to increase the use of telehealth or other remote communication technologies by cancer patients and care providers in the NWT.

YUKON

SAFEGUARD HEALTH AND WELL-BEING

- Respite services are available at all Yukon Continuing Care residential care facilities for periods of up to four weeks.
- Yukon Home Care Program provides an array of health-related services for Yukoners of all ages in the home and community setting, including temporary relief for clients and family members through respite care.
- The Teslin Tlingit Council, a self-governing First Nation based in Teslin in Southern Yukon Territory, provides home-based.support.services to assist individuals in their own homes, and provides relief to family members.

MINIMIZE FINANCIAL BURDEN

• Yukon offers <u>social assistance</u> for individuals unable to meet their basic living costs.

ACCESS TO CARER SUPPORT SERVICES AND PATIENT CARE RESOURCES

- The Yukon Palliative Care Program provides clinical and psychosocial (cultural, emotional, mental, social) support to Yukoners (and their families) living with a life-limiting illness, with the goal of achieving the best possible quality of life, until the end of life.
- The Yukon Department of Health and Social Services offers a <u>Mental Health</u> Caregiver's Support Group.
- A comprehensive overview of services and supports available to seniors in the Yukon is available at Government of Yukon's Services for Seniors page.
- <u>Alzheimer's Yukon</u> offers educational resources for dementia caregivers (DVD, telephone education, webinars).
- The Whitehorse General Hospital offers First Nation Patient Support Services, which include First Nations Mental Health Advocate and Liaison Workers to provide emotional, spiritual and social support, as well as facilitate communication between the patient, their family and hospital staff.

SUPPORTIVE WORKPLACE ENVIRONMENT

• Unpaid, job protected leaves under <u>Yukon Employment Standard Act</u> include Compassionate Care Leave (up to 8 weeks unpaid), Critically Ill-Child Leave (up to 37 weeks unpaid) and Bereavement Leave (up to 1 week unpaid)



- Whitehorse General Hospital
 (WGH) has a highly collaborative
 and specialized team that
 provides a comprehensive range
 of care and is better able to
 support cancer patients closer to
 home. Cancer Care Navigator is
 also available to support cancer
 patients and their families with
 someone to turn to with any
 questions or help accessing a
 number of community supports.
- Financial assistance may also available through the Yukoners' Cancer Care Fund, which helps Yukon residents fighting cancer, and their families who help to care for them, cover some of the substantial out-of-pocket costs that can be incurred during cancer treatment.
- Yukoners recently diagnosed with breast cancer and who receive chemotherapy at WGH or are required to travel outside the territory for care may be eligible for financial support through the Karen J. Wiederkehr Memorial Fund.

CONTINUING THE MOMENTUM

The Canadian public eye and political agenda are increasingly focussing on the well-being of carers. A great deal has been accomplished; but there is more to be done.

We believe through true partnership and commitment between all parts of society, we can continue to shape policies, build programs and adopt all-inclusive legislation that supports carers and ensures the continued health and prosperity of Canadians. We must continue to strengthen awareness and recognition of carers' contributions to the health and well-being of Canadians, the sustainability of our health care system and the viability of our economy. Through catalyst funding, the federal and provincial governments can support organizations in conducting research and implementing initiatives that lead to the development of new approaches and innovative ways to support carers. Health and community care organizations, care providers, as well as service providers, have a role in engaging carers as partners in care and invite their participation in decisions that impact them and the person they care for. As technology continues to become an integral part of our lives, we have an opportunity to create new options for care delivery that enhance our health and social care systems. Employers must be encouraged to create workplaces that understand and respect caregiving obligations. Educational environments must be made aware of the burden placed upon young caregivers and must adapt accordingly to provide the necessary supports.

The contributions carers make - to help seniors with frailty, safely live at home, to support individuals with long-term chronic diseases be independent and active members of the community and to enable loved ones to choose to die at home - are invaluable. Together, we can continue to work toward a pan-Canadian Carer Strategy and ensure carers are provided with the support they need and deserve.

Collectively, we can make a difference.

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