

## Organizations Advocating for and Supporting Family Caregivers



THE **CHANGE**  
FOUNDATION  
ENGAGE, EXPLORE, EVOLVE

**Summer 2018**

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## Acknowledgement

The Change Foundation would like to thank the following people who undertook background research to compile and update the resource documents:

- Wendy MacLellan, who completed a practicum to support her Master of Health Sciences at the University of Toronto’s Institute for Health Policy, Management and Evaluation;
- Fatimah Atcha, who completed an internship to support her Master of Public Policy at the University of Toronto’s School of Public Policy and Governance; and
- Cayla Baarda, hired as a Research Assistant at the Foundation after completing her Masters in Public Policy from the School of Public Policy and Governance, University of Toronto.
- Christal Huang, who completed an internship to support her Master of Public Policy at the University of Toronto’s School of Public Policy and Governance.

The Change Foundation also acknowledges the important work of *Carers Canada*, the *Canadian Home Care Association*, and the Canadian Cancer Action Network, whose report served as an essential reference for the completion of this resource.

## Introduction

The Change Foundation’s strategic goal is to improve the experience of family caregivers as they help their family member transition through and interact with Ontario’s health and community care systems.<sup>1</sup> The purpose of compiling this list of organizations is to provide access to practical resources for individuals and groups who want to support the “how to” of improving the experience of family caregivers. The Change Foundation came across these resources as we deepened our understanding of the breadth and depth of the family caregiver experience.<sup>2</sup> Some of these resources may be useful to others who are trying to support family caregivers.

The Change Foundation intends to update these resources on a regular basis. The Foundation welcomes feedback as well as additions and updates on resources, key documents and organizations or networks.

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<sup>1</sup> See *Out of the Shadows and into the Circle: partnering with family caregivers to shift Ontario’s healthcare system*.

<sup>2</sup> As part of the 2015-2020 strategic plan, The Change Foundation gathered data and engaged with caregivers, patients, and providers. We compiled this list through environmental scans as well as conversations with key informants. The inclusion of organizations has not been via a systematic review using inclusion themes and criteria.



## Organizations Advocating for and Supporting Family Caregivers

The Change Foundation has compiled a list of key organizations and networks that advocate for and provide support to family caregivers in Ontario, at the national level, in other jurisdictions in the U.S. and Europe, as well as international organizations.

### **Please note:**

This is by no means an exhaustive list of dedicated organizations. In addition, inclusion on the list is not necessarily an endorsement of the services and products of the organizations given that we have not assessed any of the organizations against a quality filter. We have tried to indicate, where possible, services that are publicly available and those which are provided for a cost. Organizations marked with an asterisk (\*) indicate that some services are available for a fee. The Foundation intends to add to this list as we continue to learn about these groups and the important work that they carry out on behalf of family caregivers.

## Ontario

### **General Supports and Services**

[The CaregiverExchange](#) is a mini-site of thehealthline.ca, a partnership between thehealthline.ca Information Network, a non-profit organization, and the Community Care Access Centres of Ontario. The site aims to connect family caregivers with a wide range of information, services, and supports available in their communities.

[The Caregiver Project for Seniors](#) is operated by the Alzheimer Society of Toronto but is a non-disease specific program to help maximize autonomy, capacity, and resiliency of individuals who are primary caregivers of older adults. The program allows eligible participants in the Toronto area to identify their priorities and self-direct support and funds based on their specific needs.

[Caregiver ReCharge](#) provides respite support for caregivers of those with high needs. Distinct from away-from-home respite programs, Caregiver ReCharge collaborates with community partners so that trained staff temporarily assume caregiving responsibilities in the recipient's home. These in-home support services are available at any time of day, and there is no cost to caregivers who wish to participate. The program was developed by the Mississauga Halton Local Health Integration Network (LHIN) and serves the communities of Oakville, Milton, Halton Hills, Mississauga, and South Etobicoke.



[The Community Navigation and Access Program \(CNAP\)](#)<sup>3</sup> is a network of over 30 community support service (CSS) agencies in the Toronto area collaborating to improve access and coordination of support services for older adults, their care providers, and health care stakeholders. CNAP aims to ensure that older adults and their families can easily be connected to the right service provider in their area.

[Developmental Services Ontario](#) funds the [Passport](#) initiative that offers program and financial support to adults 18 years or older with a developmental disability as well as their caregivers.

[Engagement to Reduce Isolation of Caregivers at Home and Enhancing Seniors \(ENRICHES\)](#) is a collaborative of six interconnected projects working to reduce social isolation among older adults who are caregivers. As part of the collaborative, the Canadian Mental Health Association of Ontario leads [Living Life to the Full for Older Adult Caregivers](#), an 8 week course for caregivers aged 55 and older living in Toronto.

[Koschitzky Centre for Innovations in Family Caregiving](#) at Baycrest, is a leading-edge centre offering a range of programs and services to help family caregivers cope with the physical and emotional demands of looking after a loved one.

[Ontario Caregiver Organization](#) was announced in Spring 2018 as a not-for-profit entity that will improve the caregiving experience for Ontario's caregivers by providing a one-stop resource where they can go to seek supports and services. In planning and delivery, the organization will be guided by caregivers. The organization will provide or coordinate a range of supports at the individual, organizational and system levels.

[Wesway Family Directed Respite Funding](#) is a unique respite program taking the approach that families know best when it comes to the frequency, duration, and type of break a caregiver needs. Family caregivers decide how they would like to receive their respite and Wesway pays for the approved costs. Funding is available to eligible family caregivers who provide ongoing care to a child, adult, or senior living in the City and District of Thunder Bay.

## **Condition-specific Supports and Services**

[The Alzheimer's Society of Ontario](#) has been dedicated to improving the quality of life for Ontarians living with Alzheimer's disease and other dementias and advancing the search for the cause and cure. The Alzheimer's Society's mission is to alleviate the personal and social consequences of Alzheimer's disease and other dementias and to promote research. This

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<sup>3</sup> The CNAP phone line is a free service connection and information line, but some of the services offered by participating agencies have a fee.



mission is two-fold; for patients and for caregivers. The Alzheimer's Society takes an interest in providing support through information and programs for caregivers. The Society operates [First Link®](#), a referral program designed to help newly diagnosed people with dementia get the help they need as soon as possible. This unique program ensures that family members are immediately contacted after a diagnosis so that they can develop competency and resilience in facing their caregiving journey with dementia.

[Family Association for Mental Health Everywhere \(FAME\)](#) is a registered charity brought together by families with a mission to facilitate the development of resilience for families living with mental illness. The charity provides support, education, coping skills and self-care strategies for families and caregivers.

[Gilda's Club Greater Toronto \(GCGT\)](#) is a registered charity that provides support, education, and social interaction for cancer patients and their families. The inclusive program adopts a "whole family" approach so that friends and family of all ages can receive the support they need free of charge.

[Mood Disorders Association of Ontario \(MDAO\)](#) is a registered charity that offers free support and recovery programs to people across Ontario living with depression, anxiety, or bipolar disorder. MDAO's [Family Matters Peer Support and Recovery Program](#) is a comprehensive program for family members who are providing and receiving care to those living with mood disorders and/or addictions, including educational resources, recovery programs, peer support groups, and system navigation.

[Mount Sinai Hospital Reitman Centre for Alzheimer's Support and Training](#) is a comprehensive dementia care program that provides dementia caregivers with support, skills-training, and problem-solving techniques to deal with the challenges and emotions linked to Alzheimer's disease and related dementias. Caregivers may partake in this 12-week program upon referral from a family physician.

[Ontario Dementia Caregiver Needs Project](#) is part of the Murray Alzheimer Research and Education Program at the University of Waterloo. It is a multi-phased, province-wide project focused on identifying the needs of community-based caregivers of persons with dementia and examining the extent to which community health and social support services are meeting their needs.

[Respiteservices.com](#) is a website from the Ontario government that provides information and links to respite services for people with disabilities and their families. This website represents



respite service agencies that are funded by the Ministry of Community and Social Services and the Ministry of Children and Youth Services.

### **Caregiver Advocacy, Research and Education**

[The Balance of Care Research Group](#) is affiliated with the University of Toronto's Institute of Health Policy, Management, and Evaluation, as well as Ryerson University and is housed with the Canadian Research Network for Care in the Community (CRNCC). The CRNCC is a knowledge translation and exchange network that aims to link people to knowledge about community care and caregiving.

[Concerned Friends of Ontario Citizens in Care Facilities](#) is a non-profit corporation and registered charity dedicated to reform of the long-term care system and improvement of quality of life for residents. Their goals are to address quality issues, bring concerns to the general public, provide information, and help families advocate on behalf of their relatives in long-term care facilities. They have representation and partner on projects with the Ontario Caregiver Coalition.

[Ontario Community Support Association \(OCSA\)](#) represents the Home and Community Support sector in Ontario. OCSA has a website on Home and Community Support where caregivers can use a search engine to find supports and services.

[Ontario Family Caregivers' Advisory Network \(OFCAN\)](#) is a non-profit volunteer organization that seeks to develop a community of Ontario family caregiver organizations in mental health and addictions through information sharing, supporting strong partnerships, and providing a collective voice.

[Patient Advisors Network](#) is a not-for-profit community of people who have received health services or cared for those who have, and who are committed to improving healthcare as advisors in transforming healthcare.

### **Young Carers Initiatives**

[Alzheimer Society of Toronto](#) created the **Young Carers Meetup** program, a series of in-person and online meetings for young carers to discuss self-care, responding in difficult situations, and maintaining relationships with their other family members and friends.

[Emily's House](#) at [Philip Aziz Centre](#) is a children's hospice that extends their support services to young carers who are siblings to a child or youth with a life-limiting or terminal illness and healthy children who have a parent or guardian living with a life-limiting or terminal illness.

[Family Association for Mental Health Everywhere \(FAME\)](#) is a registered charity brought together by families with a mission to facilitate the development of resilience for families living with mental illness. The charity provides support, education, coping skills and self-care strategies for families and caregivers.

[Gilda's Club Greater Toronto \(GCGT\)](#) is a registered charity that provides support, education, and social interaction for cancer patients and their families. The inclusive program adopts a “whole family” approach so that friends and family of all ages can receive the support they need free of charge.

[Heart House Hospice](#) provides grief and bereavement support to dying patients and families, including caregivers and children, in their homes so that people can receive end-of-life care at home. Their [Children and Youth Grief Network](#) and [Helping Us Understand Grief](#) programs help young carers understand their caregiving role and learn to cope with the emotions of caregiving.

[Huntington Society of Canada](#) is a not-for-profit organization that supports people and families living with Huntington Disease through counselling services and medical research. The [Youth Mentorship Program](#) allows young carers caring for someone with Huntington Disease to meet a mentor with similar experience.

[Roger Neilson House](#) is a pediatric palliative care hospice on the campus of the Children's Hospital of Eastern Ontario. The **Spectacular Incredible Braving Siblings (SIBS) Program** supports siblings of children with life-limiting illnesses. Young carers learn about self-care and coping strategies for their emotions, as well as information relevant to their sibling's illness.

[The Teresa Group](#) is a community-based charitable organization that provides support to children and families affected by HIV and AIDS. [Various support groups](#) and a [summer camp program](#) offer young carers an opportunity to learn about coping with the stigma of HIV and AIDS and the stresses of their caregiving experience.

[The Powerhouse Project](#) was created in 2003 as a special project of the Alzheimer Society of the Niagara Region. Since then, its mission has grown to promote the well-being of any young carers through social, recreational and educational programs in the Niagara and Haldimand-Norfolk Regions. Hospice Toronto has also developed the YCI model for an urban setting called [The Young Carers Program](#). In Waterloo Region [The Young Carers Project](#) was launched in 2011 as a community collaborative working to educate the public about the existence and needs of



young carers. The collaborative has also developed resources and programming for young carers in the area.

## National Level Organizations

### General Supports and Services

[Canadian Hospice Palliative Care Association](#) is the national voice for Hospice Palliative Care in Canada, advocating for quality end-of-life/hospice palliative care in Canada. The CHPCA provides resources to family caregivers.

[Caregiving Matters](#) is an internet-based registered charity offering education and support to family caregivers. Run and managed by volunteers, the organization provides a Caregiver Resource Directory, podcasts, and free workshops.

[Canadian Virtual Hospice](#) is Canada's largest repository of information on palliative and end of life care to patients, family caregivers, health care providers, researchers and educators. The website provides discussion forums and professional advice free of charge.

[The Canadian Foundation for Healthcare Improvement](#) has developed a Patient Engagement Resource Hub to support patients and their families. The hub has a dedicated search function to find tools and resources intended to encourage families and caregivers to play an active role in engaging effectively with health providers and organizations. Included on the hub is a [Toolkit for Working with Family Caregivers](#), and a [Roadmap for Patient and Family Engagement in Healthcare](#).

[The Caregiver's Lighthouse](#)\* is a community for caregivers that offers workshops, guides, coaching and peer support groups. In addition to caregiving guides, podcasts, and keynote addresses, founder and caregiver Lorna M. Scott offers consulting services for employers wishing to support family caregivers in the workplace.

[Family Caregiver's Voice](#) is a family caregiver-led group that promotes local caregiver support groups and encourages self-advocacy. Family Caregiver's Voice has launched a Family Caregiver Working Group with Patient's Canada, offers presentations as part of their awareness campaign, and has started PaCER, Patient and Community Engagement in Research, in Toronto.

[Home Instead Senior Care](#)\* offers in-home care services in a number of cities across Canada. Founded by two caregivers, the agency seeks to provide a personalized approach to meet each family's unique homecare needs. Home Instead also provides a number of resources specifically



for caregivers, including a free monthly newsletter and a resource website called [CaregiverStress.com](http://CaregiverStress.com).

[Huddol Events](#) provides a free, bilingual and confidential program to connect and support caregivers and families through tele-learning. They host learning sessions for caregivers by telephone and the web on a range of topics.

[Information for Caregivers Portal](#) provides an interactive map of Canada linking to federal, provincial and some municipal resources on financial information, care options, powers of attorney, health, mental health, and dementia.

[Saint Elizabeth Health Care](#)\* is a non-profit, health care innovator providing services across Canada. The organization provides home and community care through regional health authorities and privately as well as researching and consulting across the health care continuum. [Elizz.com](#) is powered by Saint Elizabeth Health Care and delivers services and support for those caring for others.

[Thefamilycaregiver.com](http://Thefamilycaregiver.com) is “Canada’s Home Care and Family Caregiving Resource”. The website provides articles, resources, tips and online forums for caregivers across Canada.

[Victorian Order of Nurses \(VON\)](#)\* is a non-profit charitable organization created for the purpose of home care and social services. In their homecare role, the VON interfaces with informal caregivers to provide resources, information, tools and support. They are also dedicated to innovative health services and to influencing Canada’s health and social policies.

[We Care Home Health Services](#)\* is Canada’s largest independently owned homecare service provider. We Care’s Family Caregiver Guide provides information to help caregivers manage the challenges and responsibilities of providing care to a loved one. The guide was prepared with help from caregivers and offers tools, tips, and resources for the caregiving journey.

### **Condition-specific Supports and Services**

[Alzheimer’s Society of Canada](#) is the leading not-for-profit health organization working nationwide to improve the quality of life for Canadians affected by Alzheimer's disease and other dementias, and their caregivers. The Society operates [First Link](#)®, a referral program designed to help newly diagnosed people with dementia get the help they need as soon as possible. This unique program ensures that family members are immediately contacted after a diagnosis so that they can develop competency and resilience in facing their caregiving journey with dementia.



[Autism Canada](#) is a registered charity and amalgamation of the Autism Society Canada and Autism Canada Foundation. Autism Canada's mission is for Canadians to have a united national voice focusing on the issues that affect individuals living on the spectrum and their families. The [Autism Junction](#), as well as the Family Support and Resource Staff, provide a comprehensive database of resources and supports for parents and caregivers.

[Cancer Chat](#) is an online support resource for people and families affected by cancer, funded by the de Souza Institute at University Health Network. Cancer Chat has online support groups for family caregivers caring for a family member, friend, or loved one with cancer to support, encourage, and share recommendations.

[Canadian Association for Community Living](#) is a family-based association assisting people with intellectual disabilities and their families to advance inclusion. Their website includes information for families and caregivers of people with intellectual disabilities.

### **Caregiver Advocacy, Research and Education**

[Canada Cares](#) has a mandate to recognize and to elevate the role of family and professional caregivers while establishing multi-disciplinary, multi-sector partnerships that focus on recognition, participation, awareness, accessibility and diverse community engagement. Canada Cares encourages families, workplaces, governments, industry and other stakeholders to support caregivers for children, teens, adults and seniors to recognize the importance of caregiving to both the quality of life and the economic and societal wellbeing of Canada.

[Canadian Abilities Foundation](#), a registered charity, has been a national leader and partner on various projects related to disability and communications. The organization partners with Canada Cares to encourage caregiver support and recognition across Canada.

[Canadian Association for Retired People \(CARP\)](#) is a national, non-partisan, non-profit organization committed to promoting social change that will bring financial security, equitable access to health care, and freedom from discrimination. Their mandate is to promote, advocate, and protect the interests, rights and quality of life for Canadians as they age. In February 2014, CARP authored a briefing note on their vision for caregiver support in Canada.

[Canadian Family Advisory Network \(CFAN\)](#) is a network of family advisory groups across Canada. Supported through a partnership with Canadian Association of Pediatric Health Centers (CAPHC), these advisory groups are associated with hospitals, hospices, health regions and rehab facilities across Canada. Their mandate encourages and engages family participation in



the creation of family-centered healthcare for children and families throughout Canada. In addition, CFAN encourages family member inclusion in the national, provincial, and regional healthcare debate, while serving as a collaborative agent to improve the health of children across Canada.

[Canadian Frailty Network \(CFN\)](#) is Canada's network for older Canadians living with frailty. Funded by the Government of Canada's Network of Centres of Excellence program, CFN funds research that supports patients and their families/caregivers in navigating the healthcare system and making decisions at different points throughout patients' different stages of care, especially near end-of-life.

[Canadian Home Care Association \(CHCA\)](#) advances excellence in home care through leadership, awareness, advocacy and knowledge. As a national association, the CHCA is a "unifying force" which amplifies members' individual voices to influence national policy directions on key professional and political issues. One of the Association's strategic priorities is family caregivers. The CHCA is a member of the International Alliance of Carer Organizations (IACO).

[Carers Canada](#) is a not-for-profit organization that seeks to ensure the recognition and inclusion of carers in social policy. Through a virtual network of diverse partner organizations, Carers Canada is committed to engaging and listening to caregivers, collaborating with stakeholders, and enhancing quality of life for all Canadian carers.

[Family Caregiving for People at the End of Life](#) is a pan-Canadian research team focusing on palliative and end of life care. The team has prepared a number of resources for family caregivers, including: a summary of the compassionate care benefits program; a hospice and palliative care fact sheet and a guide on how to support a family caregiver.

[Patients Canada](#) is a patient-led organization that aims to increase the voice of the patient and families in Canada's healthcare system. Its vision is for patients and caregivers to be active participants in the transformation of our healthcare system. Patients Canada uses patient and caregiver experiences to inform performance improvement targets for healthcare organizations; educates healthcare organizations on how to partners with patients and caregivers; develops and supports members to collaborate as patient leaders; and research and publish from the patient perspective.

[Public Health Agency of Canada](#) aims to promote and protect the health of Canadians through activities such as health promotion; prevention and control of chronic disease and injury;



prevention and control of infectious disease; preparation for and response to public health emergencies; and strengthening intergovernmental collaboration on public health and facilitating national approaches to public health policy and planning. The PHAC has developed a resource for caregivers: *Responding to Stressful Events: Self-Care for Caregivers*.

[The Vanier Institute of the Family](#) is a national, independent, charitable organization that conducts research to understand the diversity and complexity of families and family life in Canada while considering social, economic, environmental, and cultural factors. The Vanier Institute has published research focused on caregiving and work, such as how employers can support their employees who are caregivers at home.

## Other Provincial Organizations

### Alberta

[Caregivers Alberta](#) is an advocacy and research organization seeking to raise the profile of, and public support for, caregivers throughout Alberta. Founded in 2001 by a group of caregivers, the organization has been expanding its reach using partnerships and community collaborations. Through a grant from the Ministry of Health, Caregivers Alberta now has support programs, such as [COMPASS for the Caregiver](#), [Caregiver Advisor](#), [Caregiver Information Sessions](#), and the [Caregiver Connection Centre](#), available to caregivers in more than 30 communities across Alberta.

[Alberta Caregiver College](#)<sup>®\*</sup> is a virtual college dedicated to providing courses to enhance the knowledge and skills of family caregivers. The educational programs were developed by the Glenrose Rehabilitation Hospital, Alberta Health Services, with contributions from other partnering organizations in Alberta. Example courses include *Powerful Tools for Family Caregivers* and *Support for Caregivers of Older Adults*.

[The Family Caregiver Centre of Calgary](#)<sup>\*</sup>, the first of its kind in the province, is run by Alberta Health Services and the Calgary Health Trust. The Centre is located within Bridgeland Seniors Health Centre and offers support services, education programs, a library, and connections to health and community services.

[Research on Ageing Policy and Practice \(RAPP\)](#), at the University of Alberta, is committed to making a meaningful difference in the lives of older adults and their families by bridging research, policies, and practice. RAPP's research focuses on care and support of older adults and adults with chronic illness or disability, costs incurred by family and friend caregivers, contributions and social inclusion, and age-friendly rural communities.



## British Columbia

[Family Caregivers of British Columbia](#) is a non-profit registered charity offering a number of community-based support groups, education, resources, and referrals for family caregivers. Family Caregivers of B.C. promotes the significance of the family caregiver's role and contribution in the healthcare system and provides an [Information Package for Family Caregivers](#) that is designed to help caregivers assess their emotional, physical, and social needs and level of stress. Family Caregivers of B.C. is partnered with the B.C. Ministry of Health's [Patients as Partners](#) initiative to increase support for family caregivers through the Family Caregiver Engagement Program.

[British Columbia Psychogeriatric Association \(BCPGA\)](#) is a professional multi-disciplinary interest group that aims to support older adults with (or at risk of) mental health problems, and their caregivers, to achieve quality of life. The BCPGA facilitates quality care by supporting clinical practice, education, advocacy, research, and policy development in the field of seniors' mental health. [BCPGA provides a Caregiver Toolkit.](#)

## Manitoba

[Rupert's Land Caregiver Services](#) is a non-profit organization that provides support and services for those who care for an older family member in Winnipeg. The organization provides assisted transportation (operated by donation), support groups, respite programs, referrals, and telephone support.

## Newfoundland and Labrador

[Caregivers Out of Isolation Newfoundland and Labrador \(COI-NL\)](#) is a provincial program committed to supporting caregivers of all ages. The program provides information for caregivers through a phone line and newsletter, delivers educational presentations, runs caregiver support groups, and offers a comprehensive [Guide for Caregivers.](#)

## Nova Scotia

[Caregivers of Nova Scotia](#) provides free programs, services, information and advocacy for unpaid, family and friend caregivers.

[Nova Scotia Centre on Aging](#) conducts research on aging and [caregiver assessment.](#)

## Quebec

[Regroupement des aidants naturels du Québec \(RANQ\)](#) is an organization in Quebec that aims to improve the quality of life of caregivers in Quebec. Through the En route avec le Trousseau



project, they have created a [Toolbox](#) that facilitates partnership between organizations and caregivers.

## Saskatchewan

[Saskatoon Council on Aging](#) is a community-based non-profit organization that works towards positive aging. The website has a list of caregiver resources ranging from communication, legal and financial information, long-distance caregiving, and caregiver burnout, in addition to their [Caregiver Resource Guide](#). In partnership with the Saskatoon Public Library, Saskatoon Health Region, and the City of Saskatoon, they have also established the [electronic resource hub](#), a one-stop information source for older adults and caregivers.

## International

### United Kingdom

[Carers Trust](#) is a major charity for, with, and about carers in the UK. The organization works to improve support, services, and recognition for anyone living with the challenges of caring. Carers Trust supports carers through a combination of UK wide independent partners, online services, and grants.

[Carers UK](#) is the UK's only membership charity for caregivers. They act as a support network and a movement for change. The charity is also a member of the International Alliance of Carer Organizations.

[The Carers Direct Helpline](#) is operated by The National Health Service (NHS) England for caregivers who have questions about their caregiving role. The helpline provides information on carer assessments, financial supports, and time off requests, and can connect caregivers with local health authorities or specialist services.

[Employers for Carers](#) is an organization with over 120 member organizations who are committed to supporting employees with caring responsibilities. They work with employers to ensure that they have the support to manage and meet the needs of working carers.

[Shared Care Scotland](#) is a national charity that works to improve the quality, choice, and availability of respite care provision across Scotland. Funded by the Scottish government, Shared Care oversees the [Short Breaks Fund](#), which provides grants to non-governmental organizations that run innovative respite support programs for caregivers.

[Working Families](#) is an organization focused on helping caregivers achieve work-life balance by providing them with legal advice such as employment rights and benefits and tax credits. The



organization also works with employers to help them create supportive workplace environments for working carers.

## United States

[American Association of Retired Persons \(AARP\)](#) is a US based non-governmental organization and interest group which advocates for people aged 50 and over. AARP has supported and advocated for changes in family caregiver legislation, participated in task forces to examine the caregiver role, written position statements, reports, briefs, and supported research on family caregiving in the USA.

[Caregiver Action Network](#) is a leading family caregiver organization in the United States, working to improve the quality of life for the more than 90 million Americans who care for loved ones. CAN is a non-profit organization providing education, peer support, and resources to a broad spectrum of family caregivers across the country free of charge.

[Family Caregivers Alliance \(FCA\)](#) is a public voice for caregivers in the USA. A non-profit community based organization, they address the needs of families and friends providing long-term care for loved ones in the home.

[National Alliance for Caregiving](#) is a non-profit coalition of US organizations focusing on issues of family caregiving. The Alliance conducts research, policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. The Alliance is dedicated to improving quality of life for families and their care recipients through research, innovation and advocacy. The National Alliance for Caregiving is also a member of the International Alliance of Carer Organizations.

## Other International Organizations

[Care Alliance Ireland](#) is a national network of voluntary organizations supporting family caregivers. The network supports member organizations in their direct work with family caregivers through the provision of information, developing research and policy in the field, sharing resources, and initiating opportunities for collaboration. It is a member of the International Alliance of Carer Organizations.

[Caregivers Israel](#) is a non-profit organization that raises public awareness to issues related to caregiving, with a belief that supporting family caregivers is fundamental to strong families and stable communities. They also provide education and programming to support family caregivers. It is a member of the International Alliance of Carer Organizations. Their website is available in English and Hebrew.



[Carers Australia](#) is the national body representing and advocating for Australia's caregivers, to influence policies and services at a national level. It works collaboratively with partners and member organizations, the network of state and territory Carers Associations, to deliver a range of essential national carer services. It is a member of the International Alliance of Carer Organizations.

[Carers Japan](#) is an organization that supports family carers through research, advocacy, and direct stress-alleviating services. It is a member of the International Alliance of Carer Organizations. Their website is available in English and Japanese.

[Carers New Zealand](#) is the national peak body supporting family, whanau, and aiga carers. The organization works to ensure awareness about the roles and needs of caregivers, in New Zealand and internationally. It is a member of the International Alliance of Carer Organizations.

[Carers Sweden](#) is a politically and religiously independent organization that supports families and caregivers. They bring a family perspective with knowledge and experience to influence and inspire care for today and tomorrow's relatives and care receivers. The association is also a member of the International Alliance of Carer Organizations. Their website is available in Swedish.

[Carers Worldwide](#) is a registered charity, based in the UK that aims to work internationally and to partner with well-established organizations to improve the quality of life of caregivers. The organization was established in 2011, became a member of IACO in 2014 and has since conducted programs in North and South India on issues facing caregivers globally. It is a member of the International Alliance for Carer Organizations.

[Central Association of Carers in Finland](#) is a local association of caregivers in Finland with over 71 locations and 10,000 members. The association supports and advocates for the social rights of both caregivers and recipients of care. Information on their website appears in both Finnish and English. It is a member of the International Alliance of Carer Organizations. Their website is available in English and Finnish.

[Euro Carers](#) aims to advance the issue of family care at both national and EU levels through: raising awareness of significant contributions made by caregivers to the health and social care systems and the economy, and ensuring that EU and national policies consider caregivers.

[The French Association of Caregivers](#) is an organization that advocates for recognition of the role of carers, carer-related issues, and best practices in caregiving. It is a member of the International Alliance of Carer Organizations. Their website is available in French.



[InformCare](#) is the EU Information Hub on Informal Care hosted on the Euro Carers website. The hub offers carers and care professionals in 27 European countries free information and advice about caregiving activities as well as interactive tools to communicate with peers and exchange experiences. InformCare was part of the “INNOVAGE” EU project in collaboration with the Italian National Institute of Health and Science Aging and the Swedish Family Care Competence Centre.

[International Alliance of Carer Organizations \(IACO\)](#) was incorporated in 2012 and is seeking non-profit recognition. The organization is building a strong network of caregiver organizations across nations to share ideas, programs and research that can bring visibility and support to family caregivers around the globe. The mission of the organization is three-fold: (i) to increase visibility of family caregiving across the lifespan as an international issue; (ii) to promote the sharing of best practices in caregiving programs between countries; and (iii) to encourage and provide assistance to countries interested in developing family caregiver organizations. Full members of IACO represent caregiver organizations from around the world:

Carers Australia	Carers Canada
The Central Association of Carers in Finland	The French Association of Caregivers
Carers Worldwide	Care Alliance Ireland
Caregivers Israel	Carers Japan
Carers New Zealand	Carers Sweden
The Taiwan Association of Family Caregivers	Carers UK
National Alliance for Caregiving	

[International Federation on Ageing \(IFA\)](#) is an international non-governmental organization with a membership base of NGOs, the corporate sector, academia, government, and individuals intent on generating positive change and improving the quality of life of people as they age. The IFA hosts yearly conferences and shares information on topics relevant to the global ageing population, including caregivers.

[The Swedish Family Care Competence Centre \(SFCCC\)](#) is commissioned by the National Board of Health and Welfare Sweden to create a national overview of informal care and to collect research and examples of best practice through dialogue with carers and health practitioners. The SFCCC seeks to establish and disseminate resources that support carers and those they care for, as well as carer organizations, practitioners working in health, and policy makers.

[The Taiwan Association of Family Caregivers \(TAFC\)](#) is the first public welfare association to establish the rights of family caregivers in Taiwan. The organization is made up of individuals



and communities that care for family caregivers including: academics, nursing, doctors, occupational therapeutics, social workers, family caregivers and others that come from every corner of Taiwan. T AFC is focused on increasing public awareness for issues related to caregiving, caregiver's rights, research and development to aid family caregivers, and promote the communication and cooperation. The association is also a member of the International Alliance of Carer Organizations. Their website is available in English and Chinese.