



The **International Alliance of Carer Organizations** (IACO) is a global network of carer organizations working together to increase awareness and recognition of carers.

Global State of Caring



INTRODUCTION

There is an expectation by governments and societies that carers will provide care for those that need it. As the Global State of Caring report shows, some countries legislate this requirement and impose legal recourse for failure to do so. Whether through legislation, policies or programming, supports for the vital role of carers is necessary for sustainable health and social care systems.

Although there are invaluable benefits to providing care, being an unpaid carer can be a long-term commitment and time-consuming, taking a heavy toll on the carer's health and well-being. Furthermore, when employed carers must juggle work responsibilities with their unpaid caring duties, there are potential negative economic impacts as carers withdraw from the workplace.

The magnitude of the contributions made by carers has given rise to better awareness of, and appreciation for, unpaid care in society. The global COVID-19 pandemic has shed light on the diversity of carers, their critical role and the urgency to create a global action plan.

As global champions of carers, the International Alliance of Carer Organizations (IACO) has laid out a path for governments and international public health organisations to provide a combination of actions to sustain the contributions made by carers while successfully developing national economies. Caring is not a partisan issue, nor is it an issue unique to any particular country. We have an opportunity to learn from each other, and we must do so.

Building on the seminal work of the 2018 Global State of Care report, the 2021 edition provides a more in-depth profile of the issues, approaches, policies and innovations that are needed to support carers. More countries are included in the 2021 edition to reflect the full complement of IACO members. While the political, social and economic contexts differ depending upon the country, a clear set of carer priorities has emerged over the past decade. This report features carer initiatives within six universal carer priorities:

1. **Recognition:** Acknowledge the vital role of carers through legislation and awareness campaigns.
2. **Financial support:** Alleviate the financial burden of caring and minimize out-of-pocket expenses, income loss, pension limitations and other fiscal challenges.
3. **Work and education:** Create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work or school.
4. **Health and well-being:** Safeguard carers' physical and mental health; facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.
5. **Information and knowledge:** Empower carers through access to resources and knowledge appropriate to their needs and the stage of their journey.
6. **Evidence-informed practices:** Spread and scale innovative policies and practices that address carers' needs through integrated health and social care.

This landmark report is a step toward global collaboration on caring. It highlights the activities specific to carers and reflects, in a small way, the social and cultural climate of each contributing country. While the report is not an exhaustive compendium, it serves as a resource and a useful place from which to build.

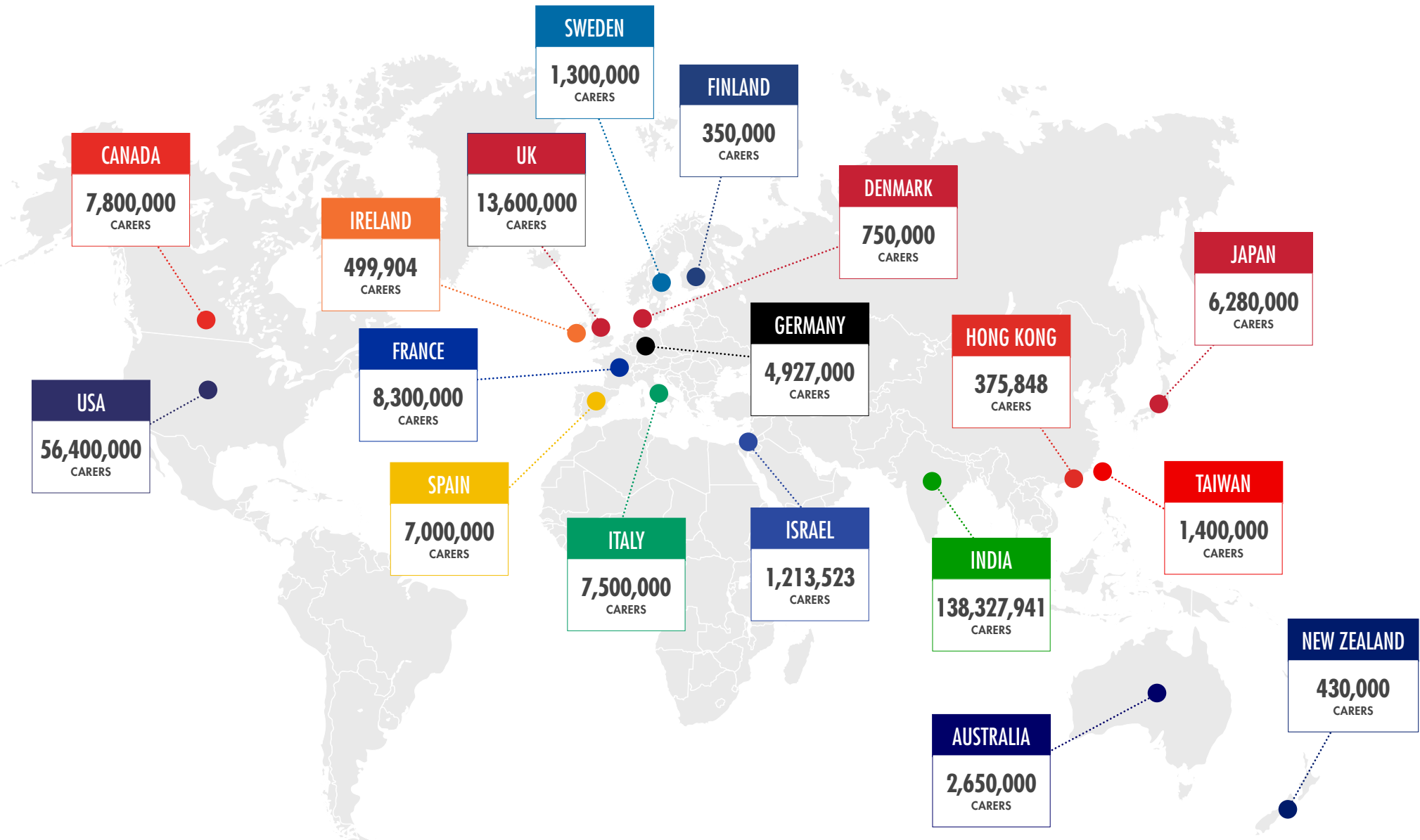
As you read the report, we encourage you to reach out to specific carer organizations and to our alliance with your insights and feedback. The members of IACO intend to continue the work of championing, destigmatising and normalising carers, and caring, globally. Once this goal is achieved, policies, practices and innovation will flourish.

Thank you for your interest and for your efforts in creating a future that honours the work of carers.

NADINE HENNINGSEN

Board Chair, International Alliance of Carer Organizations
CEO, Carers Canada

June 2021



In Australia, the term 'carer' is most frequently used. Carers are people who provide unpaid care and support to family members and friends who have a disability, a mental illness, chronic conditions, a terminal illness, an alcohol or other drug issue, or who are frail aged.

POPULATION DENSITY..... 3 per sq km*
POPULATION URBAN 85.9%*
MEDIAN AGE 37.9 years*
TOTAL DEPENDENCY RATIO..... 55.1**

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64).
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



AUSTRALIA

2,650,000¹ CARERS
10.6%² OF POPULATION

¹ [Australian Government. Department of Social Services. Supporting Carers.](#)

² Australia 2020 Population: 25,564,996 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



AUSTRALIA

LEGISLATION

The Australian Government passed the [Carer Recognition Act](#) in 2010 to increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society. The Act does not create legally enforceable rights or duties, but Schedule One provides a statement of 10 principles as to how carers should be treated.

Each of the six states and two territories have carer laws and policies:

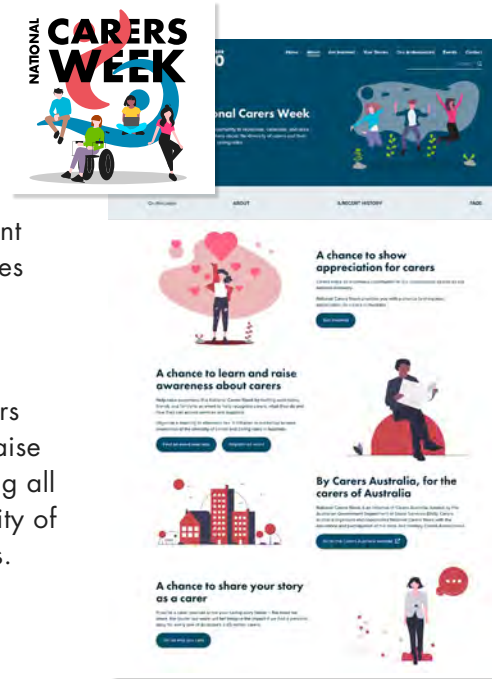
Australian Capital Territory – [ACT Carers Strategy](#)
New South Wales – [Carers \(Recognition\) Act 2010](#)
Northern Territory – [Carers Recognition Act 2006](#)
Queensland – [Carers \(Recognition\) Act 2008](#)
South Australia – [Carers Recognition Act 2005](#)
Tasmania – [Tasmanian Carer Policy 2016](#)
Victoria – [Carers Recognition Act 2012](#)
Western Australia – [Carers Recognition Act 2004](#)



RECOGNITION

National Carers Week

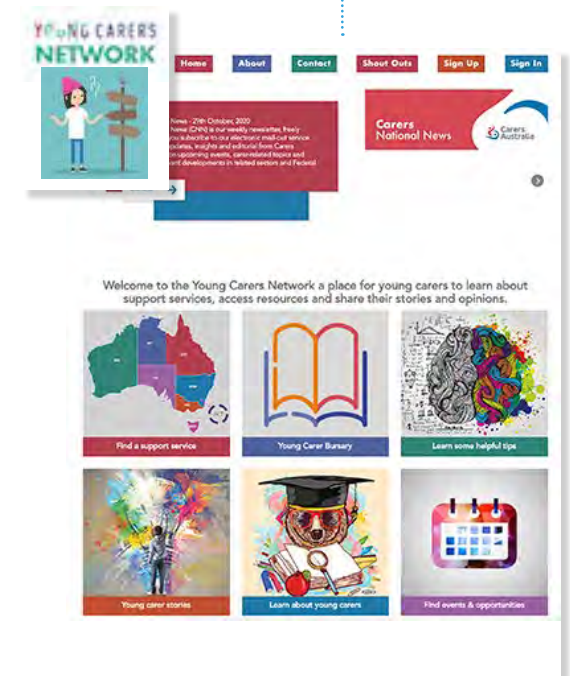
is the second week in October. It is an initiative of [Carers Australia](#), funded by the Australian Government Department of Social Services and coordinated with the assistance and participation of state and territory carer associations. National Carers Week is an opportunity to raise community awareness among all Australians about the diversity of carers and their caring roles.



RECOGNISING YOUNG CARERS

In Australia, [young carers](#) are people up to age 25 years.

Carers Australia supports a [Young Carers Network](#), a virtual platform for young carers to learn about the support services available to them, access resources and share their stories and opinions.



OPPORTUNITIES



In its [Response to Home Care Hearing on Draft Propositions](#), Carers Australia calls for the recognition of carers—as independent and vital contributors within home care as changes to the model of delivery are contemplated. The Association also alerts to the need to prepare for the growth in demand for informal carers—from around 1.25 million in 2020 to 1.54 million in 2030, a 23% total increase.

Carers Australia is calling for a whole-of-government National Carer Strategy that delivers a clear vision and strategy for all people in care relationships, now and into the future.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



AUSTRALIA

Carer Allowance is a fortnightly income supplement to assist with additional costs associated with caring. It is available to people providing care at home to a person who has a disability (including psychosocial disability) or a serious illness or who is frail aged. Criteria include: meeting an annual family income test threshold; providing daily care; and the care recipient having the illness or disability for at least six months unless it is terminal, as assessed by a professional.

Carer Payment provides income support to people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment. It is income- and assets-tested and paid at the same basic rate as other social security pensions. Assets do not include the principal home. The care must be constant, and the recipient must be someone with a severe disability or illness or who is frail aged. Nearly everyone on the Carer Payment also gets the Carer Allowance.



Carer Supplement is an annual payment to recipients of the Carer Allowance for each person being cared for.

Carer Adjustment Payment (CAP) is a one-time ex-gratia payment of up to AU \$10,000 to families in exceptional circumstances who do not qualify for any government income support payments and who experience a catastrophic event where a child under the age of 7 years is diagnosed with a severe disability or severe medical condition.

As of May 2020, the Australian Government has invested AU \$700 million AUD over five years for providing improved services and supports for carers.



OPPORTUNITIES



Research indicates that the main additional costs experienced by carers, other than increased daily living expenses, are the costs associated with acquiring and setting up IT equipment and an adequate internet connection to successfully access services, maintain social contacts and undertake work and study commitments.





WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



AUSTRALIA

WORK & CARE

Workplace accommodations are covered under the [Sex Discrimination Act](#) 1984 and the [Fair Work Act](#) 2009 that govern Australia's workplaces.

[The National Employment Standards](#) establish the minimum entitlements for employees in Australia:

- [Sick & carer's leave](#) entitles full-time employees to 10 days of paid personal leave per year; this leave is available to part-time employees on a pro rata basis.
- [Unpaid carer's leave](#) for all employees, including casual employees, allows for up to 2 days of unpaid leave each time an immediate family/household member needs care and support if the employer and employee agree and if taking a paid personal/carer's leave is not possible.
- [Compassionate & bereavement leave](#) is provided when a member of the employee's immediate family/household dies or suffers a life-threatening illness or injury.



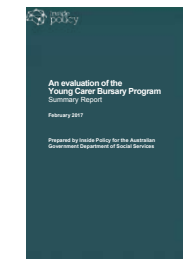
[The Australian Human Rights Commission toolkit on supporting carers in the workplace](#) provides mechanisms to support staff with caring responsibilities.

Fair Work Act 2009 provides national system employees with a legal right to request flexible work arrangements.

The [Carers + Employers program](#), available in New South Wales, defines best practice standards for supporting staff with caring responsibilities. Organisations that meet these standards can be recognised as an 'Accredited Carer Employer', enabling them to embed innovative strategies across their organisations.



EDUCATION & CARE



The [Young Carer Bursary Program](#), delivered by Carers Australia, provides financial assistance to eligible young carers to continue with their education. The Bursary is available to young carers under the age of 25, including those attending university or other approved tertiary education institutions. An [evaluation](#) of this program shows impressive positive impacts on young carers.

OPPORTUNITIES



There is a strong case for providing carer leave entitlements that are equivalent to parental leave at the time they acquire significant caring responsibilities. [Paid parental leave](#) is available to eligible employees who are the primary carer of a newborn or newly adopted child for up to 18 weeks, and paid at the national minimum wage. Employees who get paid parental leave are still entitled to unpaid parental leave.

Carer's leave should not come at the cost of their own sick leave.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



AUSTRALIA

RESPIRE CARE

The Department of Social Services funds organisations to help unpaid carers access emergency respite and provides some consumer-directed financial support that can be used for respite. Respite in the form of short-term accommodation for the person being cared for is available through the [National Disability Insurance Scheme](#) (NDIS).

Planned respite is available through the Aged Care System and consists of:

Respite in a residential aged care facility; the provider is subsidised.

Community respite provided under the Commonwealth Home Support Program (CHSP), which includes: centre-based respite available during the day. Day respite often runs from 110 a.m. to 3 p.m. and may include transport to and from the centre.

Cottage respite for overnight or weekend takes place in a dedicated respite home in the community with paid carers or in the home of a host family. It can be taken for two to three days at a time.

EMOTIONAL & SOCIAL SUPPORT

The [Integrated Carer Support Service](#) (ICSS) provides a range of services and supports for carers, such as peer support, self-guided coaching, counselling and practical skill courses. See Carer Gateway (next page).



OPPORTUNITIES



While respite is available, it is underfunded and often hard to access. In addition, there is a lack of coordination of flexible respite across different government program areas. It is anticipated that these matters will be addressed for carers of the aged in the final report of [Australia's Royal Commission into Aged Care Quality and Safety](#), expected in February 2021.



IACO is building awareness of the role and impact of carers on specific patient populations. [LEARN MORE](#)





INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



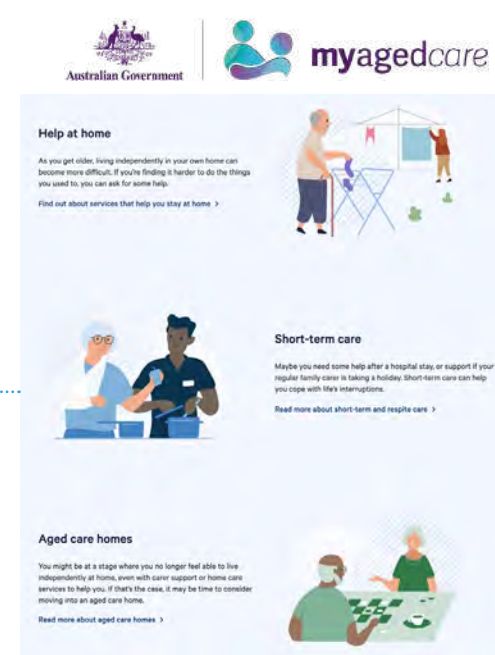
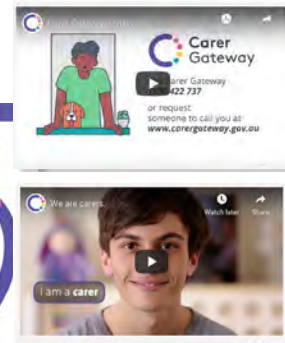
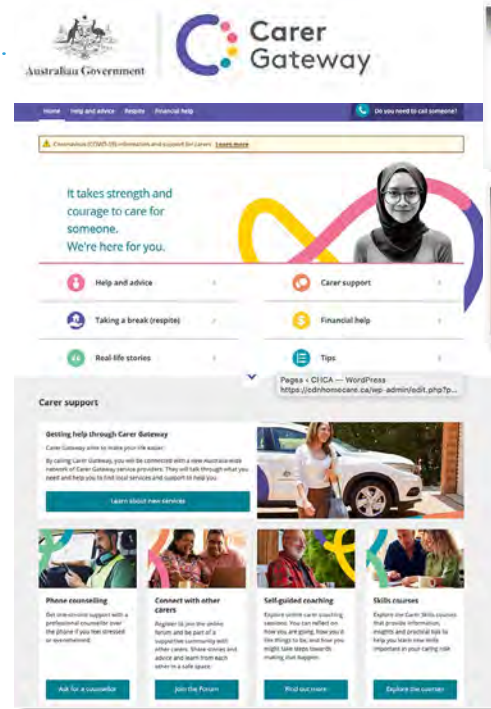
AUSTRALIA

Funded by the Australian Government Department of Social Services and service providers, the national [Carer Gateway](#) is a website and phone service that provides carers with practical information and resources to help them in their caring role. The Gateway also offers phone counselling, on-line carer forums to allow carers to connect with others, online self-guided coaching and online skills courses.

Each region in Australia has a Carer Gateway service provider. When calling a Carer Gateway Contact Centre, carers are connected with an Australia-wide network of Carer Gateway service providers. They talk through what carers need and help them find local services and support.

Carers can also access supports through other agencies to find out about services that might help them. For example, the [National Disability Insurance Scheme](#) (NDIS) supports people with a disability, [My Aged Care](#) supports elderly people and the [Department of Veterans' Affairs](#) supports veterans.

There are many specific carer education sessions and carer support groups across the county.



OPPORTUNITIES



Digital inclusion refers to whether a person can access, afford and have the digital ability to connect and effectively use online technologies. With government services and supports increasingly moving to online-only options, the need to improve carer digital inclusion is essential. Without this improvement, there is a risk of increasing the 'digital divide', which will impact carer's ability to not only undertake their caring responsibilities, but also manage their own health and well-being; access education, finance services and support; and connect with friends, family and peer support.

INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN AUSTRALIA

The [Carers + Employers program](#) is an initiative in New South Wales. The programme defines best practice standards for supporting staff with caring responsibilities and provides three levels of employer accreditation. Organisations start at 'Activate' and can work their way to 'Commit' and finally 'Excel'. This enables employers to build from an initial level of support for carers in their workplace, to embedding innovative strategies across the organisation.



LEVEL 1 **ACTIVATE**

is for organisations that are beginning to develop carer-friendly workplace policies and practices. This level must be completed before progressing to the higher levels.



LEVEL 2 **COMMIT**

builds on the minimum workplace rights established in Level 1 to provide organisations with clear actions and pathways to improve carer-friendly workplace practices.



LEVEL 3 **EXCEL**

is the highest level of accreditation. It is suitable for organisations that have embedded carer-friendly workplace practices and want to be recognised as leaders.

Carers + Employers is developing a [network of progressive employers](#) across diverse industries to share best practices, promote flexibility and showcase employers that have implemented strategies to assist working carers. Network members have access to limited resources.



Carers Australia (established in 1993) is the national peak body representing Australia's carers, advocating on behalf of Australia's carers to influence policies and services at a national level. It works collaboratively with partners and its member organisations, the network of state and territory carers associations.

Special thank you to Liz Callaghan, CEO Carers Australia, for her expert advice and review of this chapter.

SOURCES:
– Carers Australia. [Pre-Budget 2020 Submission](#).

In Canada, the term 'caregiver' is most frequently used. Caregivers are family or friends who take 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.



POPULATION DENSITY..... 4 per sq km*
POPULATION URBAN 81.3%*
MEDIAN AGE 41.1 years*
TOTAL DEPENDENCY RATIO..... 51.2**

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64). The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



CANADA

7,800,000¹ CARERS
20.6%² OF POPULATION

¹ [Statistics Canada 2018](#)

² Canada 2020 Population: 37,818,548 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



CANADA

LEGISLATION

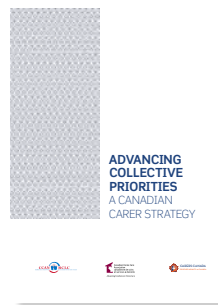
There is no federal legislation formally recognising caregivers. However, two provinces (of 10 provinces and 3 territories) have legislation that provides a list of principles relating to caregivers, their significance, rights for their recognition and support, and their value to society.

In Manitoba, Bill 42, [The Caregiver Recognition Act](#), was passed in June 2011, becoming the first province in Canada to have legislation recognising caregivers. The purpose of the Act is to acknowledge the vital role of caregivers and to set out general principles for government and agencies to promote. The Act also mandates a progress report every two years on the needs of and supports available to Manitoba caregivers.

In Ontario, Bill 59, [Caregiver Recognition Act](#), 2018, sets out general principles relating to caregivers. Ministries and government agencies may take steps to promote the general principles and may consider them when developing, implementing, providing or evaluating caregiver supports.

Public policy

Caregivers are acknowledged as vital contributors to care through publicly-funded government home care programmes which are designed to complement and supplement, but not replace, self-care with the assistance of family/friend caregivers. [LEARN MORE](#)



The province of Quebec is the first and only jurisdiction to have appointed a minister with a mandate to represent informal caregivers (2019): [Minister Responsible for Seniors and Caregivers](#).

There is an increasing trend for recognising caregivers' needs as separate from the needs of the care recipients. Caregiver assessments are conducted with more regularity, enabling a better understanding of the impact of caregiving on individuals as it relates to length of time spent caregiving and the nature of the care recipient's condition. A variety of assessment tools are used, including the [interRAI Home Care Assessment System](#) (HC), an evidence-based assessment system that informs and guides comprehensive care and service planning in community-based settings around the world. An interRAI Caregiver Survey has been developed with a total of 82 items covering a range of domains, including demographic information, physical and emotional health, caregiving responsibilities, well-being, supports and quality of life.

National Data Collection on Caregivers

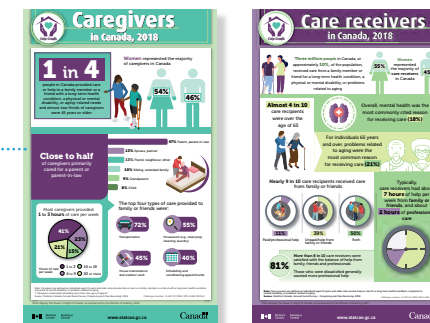
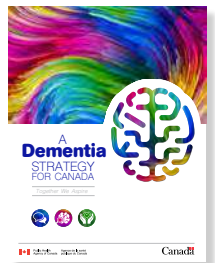
The 2018 [General Social Survey \(GSS\)](#) on [Caregiving and Care Receiving](#) collected information on Canadians who provide family and friend caregiving, as well as individuals receiving this care. A 'Care Count' series is published to delve into key trends and societal changes that influence caregiving and care receiving in Canada. Latest releases include an overview of caregivers, caregivers receiving supports, receiving care for mental illness, and experiences and needs of older caregivers in Canada. [LEARN MORE](#)

Caregiver distress is one of the six [pan-Canadian indicators](#) developed by the Canadian Institute for Health Information (CIHI) to measure access to home and community care.

National Strategies

Specific measures to support caregivers are included in the [Framework on Palliative Care in Canada](#). The framework sets out a collective vision and action plan for palliative care in Canada: all Canadians with life-limiting illness should live well until the end of life.

Improving the quality of life of those living with dementia and their caregivers is the motivation for the [Dementia Strategy for Canada](#). The strategy outlines actions to improve support for caregivers, including providing access to resources and supports.





CARER RECOGNITION (CONT)



CANADA

RECOGNITION

The federal members of the Parliament of Canada unanimously adopted the first Tuesday of April to recognise the importance of 'invisible' unpaid work, designating the day as [National Caregiver Day](#). For over 11 years, Carers Canada has led recognition campaigns marking this important day.

Across Canada, caregiver recognition is led by local advocates and celebrated at various times throughout the year. [Saskatchewan](#) celebrates and honours caregivers in the third week in March. The Manitoba and Ontario Caregiver Recognition Acts proclaim the first Tuesday in April as Caregiver Recognition Day. [British Columbia](#), [Nova Scotia](#) and [Alberta](#) recognise family caregivers the first week of May, and in [Quebec](#), the first week in November is dedicated to National Caregiver Week.



YOUNG CARERS

The [Young Caregivers Association](#), established in 2003, is the first organisation in Canada dedicated to supporting young caregivers and their families who live in rural and urban communities, while building awareness across Canada.

Caregivers under the age of 15 are not included in the Statistics Canada General Social Survey, leaving out a significant number of children and youth who provide care for a loved one.

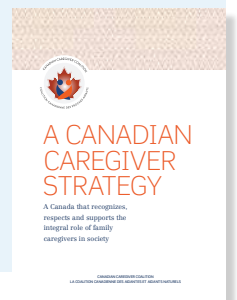
OPPORTUNITIES



Establish federal legislation defining the essential role and rights of caregivers in Canada's health and social care system.

Implement the interRAI Caregiver Survey to provide rich data to better understand

and support caregivers. Adopt a [national caregiver strategy](#) addressing five common priority areas across the country.





FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



CANADA

TAX CREDITS

[Canada Caregiver Credit](#) (CCC) is a national non-refundable tax credit that can be claimed for each infirm relative who is dependent for caregiving support because of a physical or mental impairment. Individuals are considered to be dependent for support if they require regular and consistent assistance with the basic necessities of life, such as food, shelter and clothing. The amount that can be claimed depends on the relationship to the care recipient, circumstances, net income and whether other credits are being claimed for that person.

[Medical Expense Tax Credit](#) (METC) is a non-refundable tax credit for qualifying medical expenses (such as medical supplies, dental care and travel) expensed by the caregiver.

[Disability Tax Credit](#) (DTC) is a non-refundable tax credit for the care of people with severe and prolonged impairment. The purpose of the DTC is to provide for greater tax equity by allowing some relief for disability costs, since these are unavoidable additional expenses that other taxpayers don't have to face. To be eligible, people must meet specific criteria. Being eligible for the DTC can lead to qualifying for other federal, provincial or territorial programmes such as the [registered disability savings plan](#), the [working income tax benefit](#) and the [child disability benefit](#).

[Home Accessibility Tax Credit](#) (HATC) is a non-refundable federal credit for home alterations made to assist seniors or disabled people who are approved for DTC.

[Provincial and Territorial Caregiver Tax Credits](#) are available. Some provinces (Manitoba and Quebec) offer tax credits for unpaid caregivers that are refundable, while most Canadian jurisdictions and the federal government only offer non-refundable tax credits that are treated as income.

ALLOWANCE

[Caregiver Recognition Benefit](#) provides caregivers of veterans with \$1000 per month tax free.

Nova Scotia is the only province to provide a monthly benefit to caregivers. Known as the [Caregiver Benefit](#), the programme has eligibility requirements for both the caregiver and the care recipient. The benefits are means-tested.

The Government of Canada has developed a [Benefits Finder](#) tool to help individuals find benefits and services that they may be eligible for from federal, provincial or territorial governments based on a series of questions. It does not collect or track information.

OPPORTUNITIES



Increase awareness and uptake of federal financial supports for caregivers (studies report a low number of caregivers receive government financial assistance).

Change the Canada Caregiver Credit to a refundable credit to address low-income caregivers who do not meet the threshold for income tax payments.

Reform the current Canadian public pension plans to accord value to caregivers and respond to the challenges facing employed caregivers (see Work and Education section).



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



CANADA

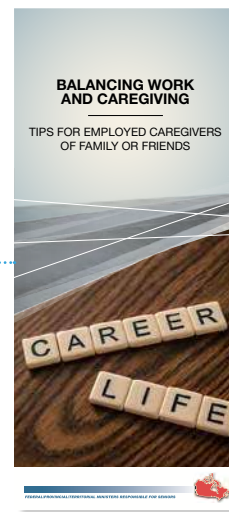
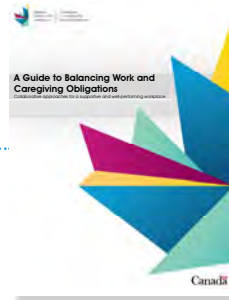
WORK & CARE

Canadian human rights law prohibits discrimination based on the grounds of family status. This means that when an employee must care for a family member, employers have a legal obligation to accommodate that employee. [LEARN MORE](#)

The Government of Canada offers online resources for caregivers: “[Balancing work and caregiver responsibilities](#)” and “[Helping employees balance work and caregiving responsibilities](#)”

There are three types of caregiving benefits available through federal [Employment Insurance](#) to support caregivers across Canada with financial assistance of up to 55% of earnings, to a maximum of \$595 per week. Caregivers do not have to be related to or live with the care recipient, but they must be considered family.

- [Family Caregiver Benefit for Children](#) – up to 35 weeks within a 52-week period to care for a child with a life-threatening illness
- [Family Caregiver Benefit for Adults](#) – up to 15 weeks to care for a critically ill adult
- [Compassionate Care Benefit](#) – up to 28 weeks for a person requiring end-of-life care



The employment standards legislation in each province and territory within Canada sets out the minimum legal requirements that an employer must follow for job-protected leaves.

All provinces and territories have incorporated ‘Compassionate Care Leave’ into their Employment Standards/Labour Code. These unpaid job-protected leaves range from 8 to 28 weeks with varying definitions for ‘family member’. [LEARN MORE](#)

‘Family’/‘Family Medical’/‘Family Responsibility’/‘Critical-Illness’ job-protected leaves are also available. For most provinces/territories, employers are not required to pay wages or benefits during the leave unless stated in an employment contract or collective agreement.

FEDERAL up to 17 weeks (critically ill adult) or 37 weeks (critically ill child) provided to federally-regulated employees

BRITISH COLUMBIA up to 5 days to ‘meet responsibilities related to the care, health or education of any other member of the employee’s immediate family’

ALBERTA up to 5 days for personal sickness or short-term care of an immediate family member

SASKATCHEWAN at the employer’s discretion

MANITOBA up to 3 days to meet family responsibilities

ONTARIO up to 8 weeks as outlined in Bill 30, [Family Caregiver Leave Act](#), 2012

QUEBEC up to 16 weeks for reasons related to an individual’s caregiver status

NEW BRUNSWICK up to 3 days as outlined in the [Family Responsibility Leave](#)

NOVA SCOTIA up to 37 weeks for ‘Critically Ill Child Care Leave’ and up to 16 weeks for ‘Critically Ill Adult Care Leave’

PRINCE EDWARD ISLAND up to 3 unpaid days as outlined in the [Employment Standards Act](#)

NEWFOUNDLAND LABRADOR up to 7 days for family leave as outlined in the [Labour Standards Act](#)

YUKON leaves are aligned with federal leaves as outlined in Bill 31

NORTHWEST TERRITORIES leaves are aligned with federal leaves for critically ill adult and child

NUNAVUT up to 5 days



WORK & EDUCATION (CONT)

A new [Carer-Inclusive and Accommodating Organizations Standard](#), developed by the Canadian Standards Association (CSA) Group with McMaster University, is available to help Canadian employers meet legal requirements, enhance work-life balance for caregivers, improve workforce retention and reduce health care costs.

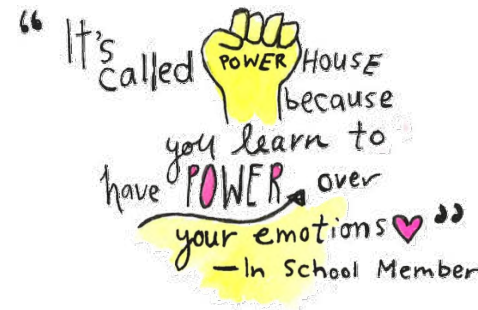
[LEARN MORE](#)

The [Vanier Institute of the Family](#), a national, independent, charitable organisation, works collaboratively with three Canadian universities to obtain and study information on caregiving and work through employers' perspectives. The initiative looks at workplace practices that provide a variety of flexible work arrangements, along with leave policies and supports to enable employees to manage their paid work and caregiving responsibilities.



EDUCATION & CARE

The [Young Carers Association](#) offers an evidence-informed 'POWERHOUSE In Schools Program' in partnership with school boards in select regions of Ontario. Powerhouse programming delivered in schools helps reduce feelings of isolation while strengthening caregiving students' capacity to cope with their life circumstances.



CANADA

OPPORTUNITIES

Recognise and provide incentives for employers to develop and support caregiver-friendly workplaces.

Standardise income replacement leaves for short-term family caregiving across the country.

Reform the current Canadian public pension plans to accord value to caregivers and respond to the challenges facing employed caregivers who may face significant consequences for their pension security when they make changes in their employment circumstances to balance work and care.

Expand programmes to support young caregivers in educational environments.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



CANADA

RESPIRE CARE

Provinces and territories set guidelines for and fund respite for family caregivers. Coverage for respite services varies across Canada. Many provinces/territories use an individual's income or income plus assets to assess eligibility for home-based respite services, with a proportion of costs to be shared by families. In other regions, no direct costs are incurred by users for home-based respite care.

Respite is typically offered through home care programmes and social or disease-based programmes and charities. Criteria vary across the country and within provinces and territories. Most jurisdictions are striving to increase in-home and/or community-based respite.

Specialised respite in Quebec includes services that replace a caregiver to provide home care to a person with a significant disability. The person stepping in to provide relief must hold a recognised diploma in an approved discipline, whether the person is employed, self-employed or from a business entity.

Adult day programmes for adults with disabilities provide daily respite for caregivers. Programmes may be offered free of charge.

Facility-based respite and adult day programmes enable unpaid carers to take extended time away.

A Caregiver Fund was established by the Government of Quebec in 2009, [Act to Establish a Caregiver Support Fund](#). The fund is dedicated to financing activities, projects and initiatives to help caregivers by:

- providing, increasing and diversifying respite services;
- providing assistance and individual, community or social support services;
- giving effective and continuous support to local communities working with caregivers;
- providing caregiver training and education services; and
- supporting innovation and the acquisition and transfer of knowledge in the area of caregiver support.

Only activities, projects and initiatives that do not come under regular programmes established or approved by the Government of Quebec may be financed by the fund.

Caregiver groups are dedicated to all caregiving and provide a wide range of direct supports in their province:

ALBERTA:

[Caregivers Alberta](#)

BRITISH COLUMBIA:

[Family Caregivers of BC](#)

NOVA SCOTIA:

[Caregivers of Nova Scotia](#)

ONTARIO:

[Ontario Caregiver Organization](#)

QUEBEC:

[L'Appui pour les proches aidants](#)

OPPORTUNITIES



Expand publicly-funded home care services to include flexible respite options with no copayments.

Create local caregiver organisations in each jurisdiction across Canada to address local needs and provide customized supports for caregivers.

Include caregiver support programmes as part of the educational offerings of all national patient disease groups (e.g., cancers, heart & stroke, diabetes, etc.).



HEALTH & WELL-BEING (CONT)



CANADA

EMOTIONAL & SOCIAL SUPPORT

Servicing the province of Quebec, [L'Appui pour les proches aidants d'âinés](#) offers two services to guide caregivers: 1) a directory listing resources by region; and 2) Caregiver Support—a free, confidential and professional phone consultation service.

The [Ontario Caregiver Organization](#) provides educational resources and support, including: a helpline (24/7); Live Chat (Mon-Fri 7a.m to 9 p.m); virtual [peer support groups](#) (groups and 1:1); and an online [list of resources and education](#) organised by caregivers' needs. They also have a dedicated [Young Caregivers Connect](#) website that provides access to support groups, information, forums and caregivers' stories.

[Caregivers Alberta](#) provides resources, mental health support and education for caregivers. These include [Caregiver Coaches](#), Caring for the Caregivers [workshops](#) and support groups such as [COMPASS](#), which is a supportive multi-session facilitated workshop that helps caregivers balance their own well-being with the challenges of caregiving.

[Service Provider Guide Understanding Caregivers](#): Developed by the Government of Alberta in partnership with Caregivers Alberta, this short guide explores caregiver stress, burnout and elder abuse, and provides practical tips to support caregivers in their practice.



[Discovery Toolkit – Supporting Family Caregivers of Seniors](#): This toolkit includes tools for learning and discussion, including summaries, slide presentations, handouts and suggested resources. The tools are based on the proceedings of and products resulting from a conference entitled Supporting Family Caregivers of Seniors: Improving Care and Caregiver Outcomes, which was held in April 2014.

[Family Caregivers of British Columbia](#) provides direct support to caregivers through a toll-free support line, [caregiver support groups](#), [health care system navigation](#) and free [educational resources](#).

[Caregivers Nova Scotia](#) provides confidential, non-judgmental [telephone and email support lines](#), as well as facilitated peer support groups. [Caregiver Tele-Connect](#), a four-week facilitated telephone support group, is also available for people giving care to a loved one who has a life-limiting illness.

[SE Health Elizz](#) offers timely content, blogs, educational resources and videos to caregivers across Canada. Elizz Coaches are available for 1:1 sessions to help caregivers plan, navigate and deal with the stresses of caregiving.

[Huddol](#) creates online communities dedicated to connecting individuals with a network of professionals and others with similar experiences across the country.



Four leading practices addressing carers' needs through integrated health and social care profiled by IACO.

[LEARN MORE](#)





INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



CANADA

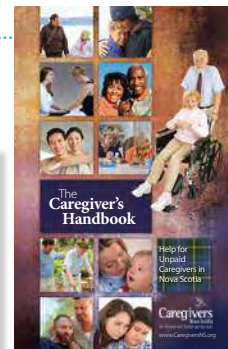
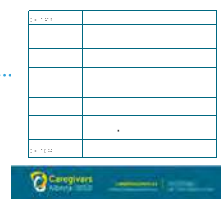
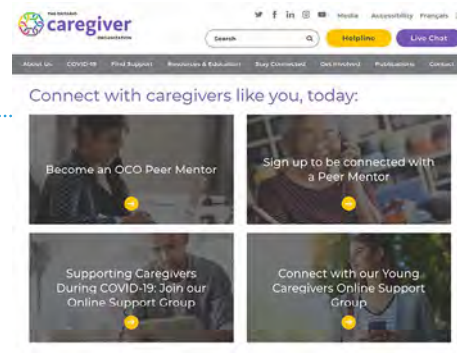
The Ontario Caregiver Organization's [SCALE Program \(Supporting Caregiver Awareness, Learning and Empowerment\)](#) aims to empower caregivers with practical information and skills to enhance self-awareness, with a focus on their own needs and well-being. The site also hosts a [community supports search engine](#).

Caregivers Nova Scotia offers [The Caregivers Handbook](#) (2018) free of charge. The Handbook is filled with tools, tips and resources to support caregivers.

[Ontario 211](#) is a free helpline that connects caregivers and others to community and social services in their geographic areas 24 hours a day, 365 days a year, in over 150 languages.

Caregivers Alberta offers a list of [helpful resources](#) and a [Finding Resource Tip Sheet](#).

In the Northwest Territories, the Continuing Care Services Action Plan – 2017/18-2021/22 commits to strengthening caregiver supports. [The NWT Caregivers Guide](#), an educational resource for caregivers on how to take on their caregiving role, is being updated.



[Ability411](#) is a web-based service that provides practical information about assistive technologies and equipment to seniors in British Columbia, their family members and their health providers. Ability411 enables seniors and the people who care for them to ask for help in identifying effective commercial technologies in cases where they are unable to find an appropriate solution on their own.

St. John Ambulance, in association with the Order of St. Lazarus, has a free nationally available online [Home Caregiver Support Program](#) (HCSP) for non-professional caregivers who are providing care for family members or friends suffering from chronic or terminal illnesses.

[Alberta Caregiver College](#) is a resource and education programme that teaches caregivers how to meet the needs of a loved one with an injury, illness or disability. Programmes include Powerful Tool for Family Caregivers (4 modules), Caregivers of Older Adults and the Caregiving Webcasting Learning Series.

OPPORTUNITIES



INVEST in technology applications to facilitate access to information and caregiver supports.

ENSURE health and social care providers have tools to recognise and support caregivers as partners in care.

CREATE 'hub & spoke' models for accessing caregiver resources (linking local and national resources).



INFORMATION & KNOWLEDGE (CONT)



CANADA

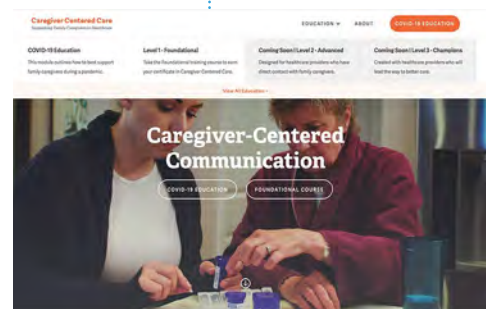
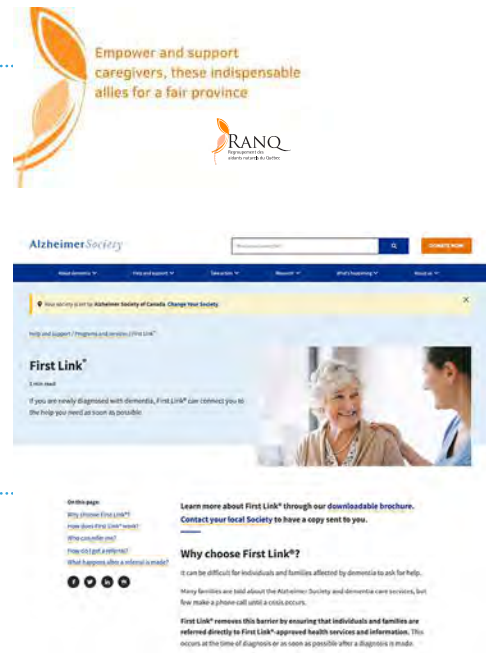
The [Regroupement des aidants naturels du Québec](#) (RANQ) is an association of community-based organisations in Quebec that work toward improving the life conditions of caregivers through advocacy, awareness and research.

The [Ontario Caregiver Coalition](#) is dedicated to raising awareness of the value caregivers add to the healthcare system and advocating for fair access to needed supports.

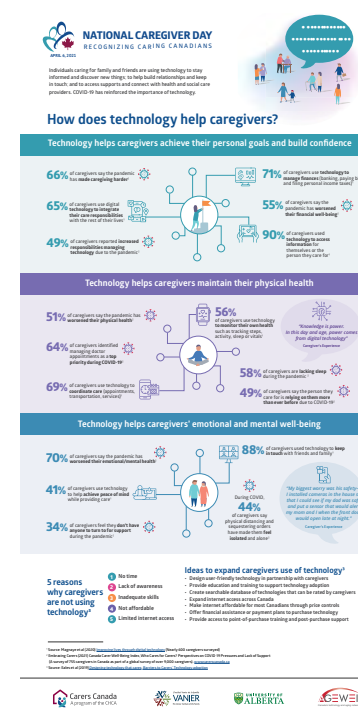
Alzheimer Society First Link® directs support for people living with dementia and their caregivers by connecting individuals with available resources in their communities. [LEARN MORE](#)

Caregiver-Centered Care Education is designed to educate all health care providers who interact with family caregivers about person-centered care for family caregivers. It is free and online, and participants receive a continuing competence certificate after completion.

Care providers, disease-specific organisations, caregiver associations, seniors and other interest groups offer a range of educational supports.



[AGE-WELL](#) brings technology-based solutions to older adults and their caregivers. Over 4,700 seniors and caregivers are involved in creating a range of digital solutions, including communications platforms, smart-home sensors, wandering-detection systems and wearables. [LEARN MORE](#)



IACO is promoting awareness and understanding of the impact and influence carers have on care recipients' health outcomes, health and social care systems and economies. [LEARN MORE](#)



INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN CANADA

[Connecting the Dots for Caregivers](#) is an initiative that focusses on improving caregivers' experiences. Local health care providers and caregivers co-design solutions that address the needs of caregivers and ensure they feel more supported, valued and engaged in their role. The project began by talking to caregivers and healthcare providers to better understand improvement opportunities. From that work, three themes were identified to help improve caregivers' experiences: awareness and recognition, communication and information, education, training and supports.

[Caregiver Readiness](#) is a national awareness and informational campaign created by Carers Canada for the federal government of Canada. The campaign includes user-friendly (language and format) tip sheets and checklists on the topic of caregiver readiness, supported by a video featuring key considerations for all Canadians who will become caregivers. Available in both official languages (French and English), the Caregiver Readiness campaign provides information on:

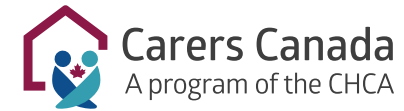
What caregiving is



What it **means** to be ready for the caregiver role

Care **conversations**: How future caregivers can engage care recipients about their care needs

Care **options**: What issues future caregivers may want to explore to better prepare themselves



Carers Canada is a national coalition dedicated to increasing recognition and support for caregivers. Through collaborative engagement, members work to build awareness and recognition of the role of caregivers and the challenges they face. Carers Canada is a priority program of the Canadian Home Care Association (CHCA).

Special thanks to the following individuals at Carers Canada who provided expertise, answered questions and participated in the review of this chapter:

- Nadine Henningsen, Chief Executive Officer
- Catherine Suridjan, Director of Policy and Knowledge Translation

SOURCES:

- Carers Canada. (2013). [A Canadian Caregiving Strategy](#).
- Government of Canada. (2020). [Provincial and territorial tax and credits for individuals](#).
- National Institutes on Ageing. (2018). [National Seniors Strategy - Supports for Caregivers](#).
- Statistics Canada. 2018. [Caregivers in Canada, 2018](#)

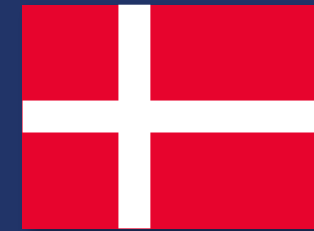
In Denmark, the term 'pårørende' is most frequently used. In Danish, there is no specific word for carer; the term 'pårørende' means both carer and relative.

POPULATION DENSITY..... 137 per sq km*
POPULATION URBAN 88.2%*
MEDIAN AGE 42.3 years*
TOTAL DEPENDENCY RATIO..... 57.3**

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64).
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



DENMARK

750,000¹ CARERS
13%² OF POPULATION

¹ [Carers Denmark](#) estimation

² Denmark 2020 Population: 5,798,813 ([Worldometer](#))



CARERS RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



LEGISLATION

Denmark does not have any laws that define and protect the rights of informal carers.

The [Social Services Act](#) addresses the care of seriously ill citizens and dying persons. The focus is on the rights of the care recipient to various services. The needs of carers are addressed only in relation to respite care (daytime care and 24h care). Local authorities determine service allocation on an individual basis with no national standards.

RECOGNITION

The [National Health Authority](#) offers thorough recommendations about how to support carers, but these are rarely met. Professional health care providers are universally encouraged, but not required, to work with carers.

In 2017, [Carers Denmark](#) instituted an annual Pårørendedagen (carers' day) held on February 2 in collaboration with one of the 98 local authorities in the country. The main event is a conference convening researchers, practitioners, politicians, NGOs and carers.



Carers Denmark and [Dane Age](#) have initiated work toward a [national strategy](#) based on five principles for improving conditions for informal carers:

1. Legal rights for carers must be improved.
2. Carers must be recognised, included and informed.
3. Evidence on carers' needs and relevant interventions must be improved.
4. Health issues and social isolation among carers must be prevented.
5. A better work-care-life balance must be provided for carers.

Thirty NGOs underwrote the strategy and it was presented to members of Parliament in November 2019.

OPPORTUNITIES



Due to extensive access to formal long-term care services, carers tend to deal only with light to moderate cases of dependency. However, budget cuts over the last 15 years have led to a shift in responsibility and tasks from professional to informal carers. As such, there are opportunities to:

- enshrine carers' rights to support in law;
- establish a national centre for research and dissemination;
- employ carer guidance counsellors in every municipality and hospital (as of 2020, approximately 15 municipalities and no hospitals employed carer guidance counsellors); and
- establish an annual carers' award for a person or organization supporting carers.

As there is no formal accommodation of young carers at this time, there are opportunities to improve the understanding of the practical, everyday impact that caring can have on children and young adults.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



CARE ALLOWANCE

A care allowance in the form of a taxable cash benefit is available for carers—who have not yet reached retirement age who care for a close relative with a disability or serious illness, or for a terminally ill relative or friend who wishes to die at home. [LEARN MORE](#)

For those who are employed, the benefit equates to 1.5 times normal sick pay; for those not employed, the benefit is a fixed amount of approximately € 1,600 (in 2020). [LEARN MORE](#)

Benefits are subject to income tax that is adjusted annually—for 2020, the rate adjustment is set at two percent. The right to the care allowance ceases at the end of the care relationship. In the event of the care recipient's death, the allowance is retained for up to 14 days. [LEARN MORE](#)

Carers retain rights to unemployment benefits, holiday pay, etc. Pension contributions are 12% of salary, with 8% contributed by the employer.

BENEFITS

Cash benefits are also provided to compensate for loss of income for parents of disabled children.

If the care recipient is under 18 years of age, and if the care needs are such that one or both parents are forced to reduce or cease paid employment (including self-employment) in order to care for the child, compensation for loss of income is available based on prior income, with a maximum of a little over € 30,000 p/y FTE. This compensation is not subject to a time limit. It is awarded based on an individual assessment by the local authority. [LEARN MORE](#)



OPPORTUNITIES



Establish formal financial guidance for carers before they have to choose to work part-time, retire early or drop out of the labour market. This will ensure they have rational and well-informed projections of the long-term financial impacts for themselves and their families. This is a particular concern given the gender imbalance in informal care.

National standards for benefit criteria should be established as decisions by local authorities can result in fewer informal carers receiving compensation as a result of local budget restraints.



The 2018–2022 IACO strategic plan outlines four strategic priorities:

- Increase awareness and recognition of carers.
- Enhance understanding of the impact of caring.
- Create global strategy and commitment to action for carers.
- Facilitate capacity building.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



DENMARK

WORK & CARE

Working carers (individuals who have a connection to the labour market) who wish to care for a closely-related person with substantial impairment of physical or mental functions or a serious, chronic or long-term illness (including terminal) in the person's home, can enter into an employment contract with the municipal council where the care recipient lives. A number of conditions must be met.

The carer can be employed for up to six months and the care period can be extended by up to three months if special circumstances warrant. The total period can be divided into shorter periods, such as one month each, and several carers can share caregiving responsibilities. However, only one award of six or nine months can be granted to a care recipient for one diagnosis. [LEARN MORE](#)

The terms of this caregiving employment are contractual and address conditions of work, including the length of the period, the work tasks, notice of termination, employment interruption and more, as would be the case in hiring a professional carer.

EDUCATION & CARE

All schools offer psychological one-on-one counselling to children finding it difficult to cope with their schooling. Student counsellors at all secondary and tertiary education facilities offer a similar service.

There is opportunity to improve understanding of the impact that caring can have on children and young adults. Aligning with current advocacy for free psychological treatment to anyone under 25 years could help increase awareness of the issues arising from caregiving by youth.



OPPORTUNITIES



In October 2018, [Carers Denmark](#) and 12 NGOs presented three recommendations to a parliamentary hearing on carers' rights to flexibility:

1. Implement carers' days with compensation for loss of income, building on an EU directive calling for carers' days.
2. Offer greater flexibility to allow several carers to share benefits.
3. Improve respite care to allow carers to continue in paid employment.

Progress has been made on the issue of benefit flexibility. Since the Danish labour market is regulated less by government edict and more by three-party agreements between government, employers' organisations and trade unions, Carers Denmark recommends that:

- trade unions adopt the issue of carers' rights (so far, only the union of professional care workers has addressed carers' rights); and,
- large employers and their organisations embrace strategies to be good employers for carers (Carers Denmark is working with one interested pharma company).



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



RESPITE CARE

Respite care is offered in three ways:

1

At an activity centre or day centre with appropriate activities, often related to maintaining activities of daily living and mainly aimed at the elderly. Transport and meals are often provided or included at a low price and the care is free of charge.

2

Within a long-term care facility where there is a charge for meals and laundry, but all other services are free. This service is variable and dependent on availability.

3

As in-home relief, usually only during normal working hours. The service is not in frequent use due to the high cost to local authorities and lack of awareness among family carers.



Companion service is similar to respite care, but for the benefit of the care recipient and only available to care recipients younger than age 67 who are permanently unable to leave their home without help. The service provides a professional carer as a companion for 15 hours per month, to be scheduled individually. The care recipient must cover all costs in connection with excursions, such as train or museum tickets, meals, etc.

CAREGIVING SUPPORT

A range of municipal services are available to help the person suffering illness or disability care for themselves. These services include rehab training, physical aids, specially adapted vehicles, handicap transportation and home alterations. This is all at no cost to the recipient, except for adapted vehicles, which are provided with co-financing. The intent of these services is to boost self-reliance and reduce the need for paid care, although the effects on unpaid care are not known.

There are also municipal services available for the personal and medical needs of the care recipient. These services include help with personal hygiene and dressing, ready-meals, medication provision and in-home nursing for minor needs. Meals are charged for, but all other services are free of charge.

Municipalities may offer help with basic household chores within narrow parameters, and normally only in the absence of a family carer able to perform these tasks.

All services are provided according to standards set by each municipality. There are significant variations across municipalities. In addition, these standards have been reduced considerably over the past 15 years due to country-wide funding cuts.



Carers account for more than twice the formal care workforce in Denmark, and more than 10 times the formal-care workforce in Canada, New Zealand, the United States and the Netherlands.

IACO Strategic Plan, 2018–22





HEALTH & WELL-BEING (CONT.)



EMOTIONAL & SOCIAL

Approximately one in six municipalities employ carer guidance counsellors, who typically offer individual support, provide information on rights and resources, run courses and/or arrange talks, and organise self-help peer groups.

Mutual carer support groups are offered by several patient organisations and [Carers Denmark](#), which recently received funding to arrange support groups across diagnoses. Groups may be managed by professionals but are more often run by volunteers, and some are completely autonomous.

Carers are eligible for treatment by a psychologist with 40% co-pay of consultation fees for up to 12 sessions. The carer must normally request help within 12 months of the traumatic event (e.g., accident, serious diagnosis or emergency hospital treatment). But, this time limit is rarely enforced. The same offer is available to carers on the death of the care recipient.

YOUNG CARERS SUPPORT

The NGO [Children, Young Adults and Loss](#) (part of the National Grief Centre) offers specialised treatment and counselling for children and young adults who have experienced serious illness among their parents or siblings, or who have lost a parent or sibling.

A few patient organisations, notably the [Danish Cancer Society](#) and the [Alzheimers' Association](#) have developed activities aimed specifically at young adult carers.

In 2020, Carers Denmark produced a [comprehensive booklet of advice for volunteers who want to start local self-help groups for carers](#).



OPPORTUNITIES



More 24 hour respite care needs to be offered. [Carers Denmark](#) continues to advocate that providing access to regular, high-quality respite will sustain carers in their roles for longer without negative consequences, thus saving government expenditures on facility-based care.

Carers Denmark believes that all municipalities and hospitals should employ a carer guidance counsellor. Although interest in this concept is increasing and municipalities are employing more counsellors, wide-spread application in hospitals and municipalities is still lacking.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



[Carers Denmark](#) offers information and tools to support carers and promote well-being. Collecting carer data, undertaking national and local advocacy, and facilitating carer networking are priorities for Carers Denmark. The organisation also offers a growing range of webinars addressing carers' concerns.

[Dane Age](#) provides extensive information on rights and support, and maintains a telephone helpline providing access to a range of area experts.

Patient organisations provide information on rights to assistance, financial support and resources—usually focussed on the care recipient. Some organisations, such as the [Alzheimer's Association](#) and the [Danish Cancer Society](#), offer telephone counselling for carers.

The NGO [Børns Vilkår](#) provides several services backed by public funding:

An advice line for children
by phone, text, chat, etc.

An advice line for
parents by phone



['Learn to manage everyday life as a carer'](#) is a national programme by the Danish Committee for Health Education supporting adult carers of people living with long-term diseases.

Over half of the 98 municipalities in Denmark have adopted the education programme, and efforts are underway to roll out the programme nationwide by 2021. The programme focusses on empowerment and self-efficacy and is taught peer-to-peer, with support from municipal and programme staff. The intervention was developed based on the Chronic Disease Self-Management Program from Stanford University. Early indications are that participants are highly satisfied with the programme and they have been empowered to improve their general well-being.

The Danish Health Authority is currently funding a project to develop a digital self-learning version of the programme.

OPPORTUNITIES



One of the five principles within the proposed national strategy for carers is the need for more and better evidence on carers' needs and relevant interventions. Carers Denmark advocates for the establishment of a National Centre for Research on Carers and Caring that would conduct research, collect and disseminate research, and act as a repository of information and resources for carers and for health professionals working with family carers. Several NGOs in Denmark support this concept.

INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN DENMARK

Carer Self-Help Groups Across Diagnoses (Pårørendegrupper på tværs): In 2019, Carers Denmark received seed funding of about US\$11,000 to investigate the need for a forum for carers where the one thing all participants have in common is the caring role.

Experience and communications from a broad range of carers have long indicated that diagnosis-specific carer groups often become focussed on how to be a good carer for the benefit of the care recipient, rather than focussing on how to manage the demands and challenges of caring to improve the carer's quality of life. The seed funding for the Carer Self-Help Groups Across Diagnoses project was provided by TrygFonden to produce materials for eight facilitated meetings per group, training of facilitators, advertising and reporting on outcomes.

The project is to be piloted in three locations (one in the capital, one in a regional town centre and one in a rural area). However, due to COVID-19 related restrictions, only the first phase of the project has been completed, and the remaining phases have been postponed until the spring of 2021.

Evaluation will be based in part on participants' self-testing using the [WHO-5 Well-Being Index](#).

If the pilot project proves its value for the participants, Carers Denmark will implement the groups as an optional add-on to the Learn-to Tackle courses.



Carers Denmark (established in 2014) works to improve the conditions of life for carers themselves, irrespective of the diagnoses or handicaps of those for whom they care. The focus is on changing policy and improving carers' rights, and to a lesser extent on providing services for carers. The association collaborates widely with others working on health policy—nationally and internationally.

Special thanks to Marie Lenstrup, National Chair, Carers Denmark, who provided expertise, answered questions and participated in the review of this chapter.

SOURCES:

- Danish Health Authority. [Website](#).
- Eurocarers. Towards carer-friendly societies. [Eurocarers country profiles \(2020\)](#).
- European Commission. (2020). [Employment, Social Affairs & Inclusion. Denmark](#).
- International Labour Organization. [NATLEX. Database of national labour, social security and related human rights legislation. Denmark](#).

In Finland, the term 'informal carers' is most frequently used. Informal carers are family members or loved ones who provide care and support to an older, disabled or ill person in their home.



POPULATION DENSITY..... 18 per sq km*
POPULATION URBAN 86.1%*
MEDIAN AGE 43.1 years*
TOTAL DEPENDENCY RATIO..... 62.4**

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and senior (ages 65+) populations per 100 people of working age (ages 15–64) in 2020. The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



FINLAND

350,000¹ CARERS
6.3%² OF POPULATION

¹ [Carers Finland](#)

² Finland 2020 Population: 5,541,862 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



FINLAND

LEGISLATION

There is no legal obligation in Finland for people to take care of their relatives, except for their children under 18 years of age. However, there is a strong cultural norm to care for parents as they age or their needs for care increase.

- The first reference to family care (paid care provided in the carer's home by a professional—not necessarily known to the family) is in the Social Welfare Act 710/1982 Ch 3 Section 26 (311/92). This law is important as it is one of the first building blocks of support for informal care.
- The first reference to informal care is in the [Social Welfare Decree of 607/1983](#). The first decree on Support for Informal Care dates from 1993.
- As part of national reform of informal care (care provided in the home by someone with whom the care recipient has a familial/personal relationship) in 2004, an investigator was appointed to develop recommendations to integrate informal care into all social and health care services.
- The [Act on Support for Informal Care](#), 2005, steers the provision of formal social services to support informal carers and care recipients.

RECOGNITION

A governmental programme for the development of informal care was launched in 2012 and has continued to be on the government agenda. The current government programme, [Inclusive and Competent Finland—a socially, economically and ecologically sustainable society](#), addresses informal care in a larger context of a fairer, equal and inclusive Finland.

The Ministry of Social Affairs and Health project, [Reform of home care for older people and informal care for all age groups 2016–2018](#), was designed to develop home care for older people and enhance informal care for all age groups. The main goals were to examine equality among older people, informal carers and care recipients, as well as identify ways to provide better coordination of services and curb the growth of expenditure. Regarding informal care for all age groups, the task was to establish best practices of informal care as well as develop a programme that includes informal and family care centres.

Various programmes, Carers Finland and local associations work to find solutions to enhancing the well-being of Finnish carers, supporting long-distance caregiving and supporting carers to combine work and caregiving.

Carers Finland, together with its member associations, organises an annual Carers Week (week 48) with some 200 local events and activities all over the country.

Carers Finland also participated in the first European Carers Day on October 6, 2020, and will continue to recognise this day in the future.

YOUNG CARERS

Finland's awareness of young carers and policy response is 'awakening'. Carer Finland's [project Jangsterit](#) (youngsters) (2016, ongoing) aims to raise awareness of young carers and the challenges they face.

The [first set of nationwide data on young carers](#) is available through the [Finnish Institute for Health and Welfare research \(2020\)](#).

OPPORTUNITIES



There are inconsistencies across the country as [310 municipalities](#) determine informal carer criteria and care allowances creating inequity. Several governments have attempted to reduce the number of municipalities (local authorities) and make counties (regional authorities) responsible for arranging informal care. The whole Finnish social and healthcare service system—including long-term care—was expected to go through a big change through the social and health-care reform (SOTE), planned to come into effect in 2020, but this was put on hold following some changes in the government. [LEARN MORE](#)

[Carers Finland](#) is striving to make informal care and its diversity visible in all policies. National criteria for granting support for informal care should be established. [LEARN MORE](#)



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



FINLAND

CARE ALLOWANCE

The [Act on Support for Informal Care](#) defines the prerequisites for granting support and the minimum care allowance, along with outlining the responsibilities of the municipalities. Those receiving support (14% of all informal carers) are called 'carers with agreement' and statistics relating to support for informal care mainly refer to them.

Informal care support can be granted for both long-term and short-term needs. There is no employment relationship between the informal carer and the municipality. The municipality holds accident insurance, which covers all injuries that occur in the care context or during related travel for the informal carer. A contact person at the municipality is also provided to the informal carer.

The municipality in which a caregiver resides may impact the financial support provided as each of the 310 municipalities determine eligibility criteria and the amount of care allowance provided.

PROCESS:

Municipality makes a decision on support and related services.

If the decision is positive, the municipality completes an informal care agreement with the carer.

The agreement determines the carer's fee and the method of payment, and describes how to arrange care when the carer is on leave from the care task.

A care plan and a service plan are appended to the agreement.

Additionally, informal carers are entitled to different social services such as:

- social work;
- child guidance and family counselling;
- home services;
- housing services;
- institutional care;
- family care;
- activities supporting access to employment and specific work for people with disabilities; and
- measures to establish maintenance for a child.

([Social Welfare Act](#)).

TAX BENEFITS

Informal carers with agreements are entitled to a:

- care allowance;
- tax deduction for expenses; and
- tax credit for domestic help or household expenses.

The income provided to informal carers through municipalities is treated as taxable and accrues pension rights (although the accrual rate is small).

There are also three levels of tax-free benefits through [Kela](#), the Social Insurance Institution of Finland, paid to people with a disability or chronic illness. These benefits can assist in retaining carer support and supporting employment. Two of the benefits are payable at three different rates.

OPPORTUNITIES



[Communicate information about the tax credits for household expenses](#). It is not well known and is mainly used by middle and upper income households, thus increasing household inequality. Applications can also be complicated.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



FINLAND

WORK & CARE

The [Employment Contracts Act 2001](#) outlines the fundamental legal provisions concerning work. The Act provides for an unpaid leave to care for a family member. Proof of need may be required and the employer must try to accommodate requests for additional leave time. [LEARN MORE](#)

A report for the Ministry of Social Affairs and Health, [Coordinating informal care and gainful employment 2019](#), by Laura Kalliomaa-Puha, is part of the government's improved home care for older persons initiative. The report explores options for informal caregivers to combine their care responsibilities with paid employment, and in so doing enhance informal care for all age groups.

EDUCATION & CARE

[Finnish Institute for Health and Welfare](#) includes young carers in their [School Health Promotion Study](#) at 4-6-year intervals. This enables monitoring of responsibilities and challenges and serves as a basis for identifying and providing support for young carers.



Approximately 28%
of working people
are carers. [LEARN MORE](#)

Income level is somewhat lower
for working-age carers than
others in the same age group.
Those that receive support for
informal care are more likely to
need income support. [LEARN MORE](#)

The leaves are relatively more
generous for those caring for a
child with special needs than for
those caring for older adults.

[\(WORK AND HEALTH IN FINLAND, 2009\)](#)

OPPORTUNITIES



[Carers Finland's Project](#) (2020–2022) addresses the need to support working-age informal carers. The impetus is the rapid increase of informal caregiving provided by working-age people as a result of the Finnish policy change promoting outpatient care.

The three main objectives of the project are:

1. creation of an accessible data bank to address demand for information;
2. development of focussed support group models; and
3. integration of the perspective of working-age carers to the ongoing social security, social welfare and healthcare reform processes, which include the national implementation of the [EU work-life balance directive](#).





HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



FINLAND

RESPITE CARE

Informal carers are provided with two to three days of statutory respite care services per month, depending on the intensity of the care according to the 2016 reforms to the Act on Support for Informal Care.

Substitute care is organized by the municipality. Options are care at home or in a facility. The municipality can hire a substitute for the informal carer from a private care provider or hire a private individual from within the family circle. The municipality establishes a formal agreement. An annually determined daily fee may be collected for the care arranged during the informal carer's statutory leave in accordance with the Act and Decree on Social and Health Care [Client Fees](#).

[Family Foster Care](#) can be provided at the care recipient's own home by travelling family foster carers or at the family foster carer's home. The municipality arranges, supports and supervises family foster care.



EMOTIONAL & SOCIAL SUPPORT



The municipality organises coaching, training and health checks (such as general state of health and health risks) for carers as determined by the individual needs of the carer and the caring situation. [LEARN MORE](#)

[Carers Finland](#), its 70 local associations and other NGOs offer peer support (groups and chats), training, information and guidance, one-on-one discussions, trips and recreation for carers.

OPPORTUNITIES



Leverage various strategies to increase access to respite care as only 54% of informal carers took the leave available to them in 2017.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



FINLAND

The [Act on Support for Informal Care](#) makes provisions for compensated informal carers to participate in training and education as well as well-being and health checks-ups. They also receive social and health-care services that support their well-being and care tasks.

Relevant information on caregiving, available support services, entitlements and benefits are available [online](#), via telephone or through local health centres or clinics, known as terveystakeskus. There are approximately 270 centres in Finland.

OSSI Project Service Counselling of informal carers in Mikkeli Carers Association (a member association of Carers Finland) [Omatori](#) (formerly Ossi-center) is a multi-stakeholder centre that brings together public, private and social sector service providers under one roof for informal and family carers.

The purpose of the OSSI project, implemented in 2016–2018, was to enhance informal and family care services and establish a customer-oriented service guidance network and a centre of expertise on informal and family care in South Savo. The project was an element of the government's key project, 'Improved home care for older persons and enhanced informal care in all age groups'. It was a collaboration between three regions and was coordinated by the South Savo Social and Health Care Authority Essote. The objective of the project was to create more equal, better coordinated and cost-effective informal and family care service. [LEARN MORE](#)

[Digital and Population Data Services](#) are currently developing a service path for those seeking information about support for informal care.

Peer chats provide a safe place online for carers to meet and exchange thoughts and ideas. This is especially important during COVID-19 circumstances. Volunteers are trained to run the chats and professionals from Carers Finland, together with its member associations, are available if the volunteers need assistance. The chats are for carers once a week for two hours. Carers Finland now offers chats to provide both information and advice on issues about informal care and peer support.

The chat can be found on [Carer Finland's web pages](#).

In addition to online, telephone and printed information, Carers Finland provides chats for information and guidance on support for informal care for carers and professionals.

A peer chat for carers began in October 2020.

Unpaid caregiving has become one of the most important social and economic policy issues worldwide. As the population ages, unpaid carers will continue to play a critical role in every society, providing substantial economic value globally.



INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN FINLAND

Ovet-valmennus[®] (training for informal carers) is a well-documented, tested and valid method to increase the knowledge, skills and well-being of carers. Ovet-training is a free group activity for carers to deal with and discuss issues related to informal care, such as change in life circumstances, basics in assisting and care work, available services and, very importantly, self-care and awareness of personal needs and well-being.

The purpose of Ovet-training is to gain peer support and help participants find their own strengths as carers and individuals. The coaching consists of eight 1.5 hour sessions (12 hours).

Carers Finland coordinates Ovet-training, which is a part of welfare promotion for informal carers. The programme is governmentally funded at the national and local level. In addition, the

programme is based on voluntary work of the associations. Half of the member associations have employed staff, but the work for the programme is done by volunteers in the community. Carers Finland provides education for instructors who organise Ovet-trainings at a local level. Carers Finland offers up to four instructor courses a year.

Ovet-training is also provided online. Alongside the basic model for training for informal carers, Carers Finland has also developed targeted training to support the various needs of carers.

Some special Ovet-training includes:

- training for carers of people with dementia;
- training for carers in working life;
- training for carers of children with disabilities and chronic diseases;
- training for carers of people with mental health problems; and
- distance training via the Internet.

Developed in 2010–2012, the programme has trained approximately 4,250 carers all over Finland to date.

Carers who have taken part in the training programme reported having more skills and knowledge and feeling better.

After the training, they reported taking more time-off for themselves, sharing their thoughts and feelings more openly, and knowing more about available support services.



Carers Finland (established in 1991) is an advocacy and support association for carers with a mission to improve the social status of families in informal care situations by influencing legislation and public opinion. Carers Finland works with 70 member associations across the country.

Carers Finland coordinates Carers Network Finland, which was established in 2005. The Network brings together 23 national organisations, foundations and research institutions working in the field of informal care. Its mission is to promote and advocate for the development of informal care and cooperation between sectors.

Special thanks to the following individuals at Carers Finland who provided expertise, answered questions and participated in the review of this chapter:

Malla Heino, Coordinator
Marjo Ring, Special Advisor in Mental Well-being
Sari Tervonen, Executive Director

SOURCES:

- Finnish Institute for Health and Welfare. [Website](#).
- Eurocarers. Towards carer-friendly societies. [Eurocarers country profiles \(2020\)](#).
- Joseph, S., Sempik, J., Leu, A. & Becker, S. (2019). Critical perspective on possible future directions. *Adolescent Research Review*, 5, 77-89.
- Kunta Litto (Association of Finnish Municipalities). [Website](#).

In France, the term 'close caregiver' is most frequently used. Close caregivers are people who provide assistance with activities of daily living on a regular, frequent and non-professional basis.

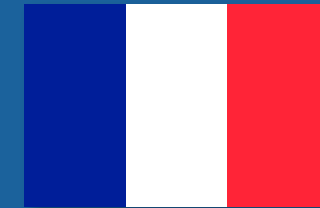


POPULATION DENSITY..... 119 per sq km*
POPULATION URBAN 81.5%*
MEDIAN AGE 42.3 years*
TOTAL DEPENDENCY RATIO..... 62.4 **

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64). The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



FRANCE

8,300,000¹ CARERS
12.7%² OF POPULATION

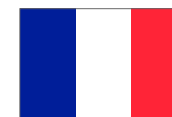
¹Enquête Handicap Santé Aidants 2008, DREES

² France Population 2020: 65,306,979 (Worldometer)



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



FRANCE

LEGISLATION

Recognition of the role of family caregivers in society started with the law of February 11, 2005, for equal rights and opportunities, participation and citizenship of people with disabilities.

An official definition was included in the [law on the adaptation of the aging society](#) (ASV), December 2015. The law does not specify the condition of the care recipient and defines a close caregiver of an elderly person as 'a spouse, the partner with whom there is a civil solidarity pact, or partner, a parent or ally, or a person residing in the home or maintaining close and stable ties, who provides assistance, on a regular, and non-professional basis, to perform all or part of the acts or activities of daily living'.

[Law n° 2019-485 of May 22, 2019, aimed at promoting the recognition of caregivers](#), promotes the awareness of close caregivers. The law includes collective bargaining measures intended to mediate between the professional and personal lives of caregiver employees. It also plans to experiment with a system of 'relaying' (a form of 'live-in' support) the caregiver by medico-social professionals.

In August 2020, the [organic law n°2020-991 relating to social debt and autonomy](#) was introduced to address the financial impact of COVID-19. It created a fifth branch of social security dedicated to risks associated with loss of autonomy and effectively addresses the needs of the caregivers for older people and those with disabilities. The organisation and financing of this branch are still under development as of the beginning of 2021.

[LEARN MORE](#)

RECOGNITION

Since 2010, France has recognised National Caregivers Day on October 6. Prior to this recognition, there was acknowledgement of caregivers related to specific illnesses, such as the first national plan against Alzheimer disease and related disorders in 2001.

[Caregivers: A New Support Strategy](#) was released by the government in October 2019. This report was informed by a report by the Ministry of Solidarity & Health, [Consultation: Old Age & Autonomy](#). The strategy identifies six priorities with 17 concrete measures along with funding and timeline commitments.

1. Reduce caregiver isolation and provide enhanced supports.
2. Establish social rights for caregivers.
3. Enable caregivers to balance personal and professional life.
4. Increase and diversify respite.
5. Promote and support caregiver health and well-being.
6. Support young caregivers.

The minister set a goal of nationally supporting 450,000 caregivers by 2022, a significant increase from the 60,000 formally supported in 2020.

A committee appointed by the General Administration for Social Cohesion (Direction générale de la cohésion sociale) (DGCS) was established to monitor the implementation of the caregiver strategy across the country. The monitoring committee first met on October 5, 2020, and plans to meet quarterly. The committee is tasked to improve the national role of the [National Solidarity Fund for Autonomy](#) (CNSA) to oversee the piloting of the various initiatives.

Recognition of the role and place of close caregivers, both in the relationship with the person being cared for and in society, is developing. Barriers between ages remain (particularly between the elderly and people with disabilities), but the decategorizing of public policies is progressing. Measures have been put in place and the issue continues to be one of rights, options and accessibility. In order to respect people's self-determination, all stakeholders must be vigilant to ensure that the consideration given to close caregivers is not accompanied by an expectation that they are instrumental to health care practice or that the role is professionalised.



CARER RECOGNITION (CONT.)



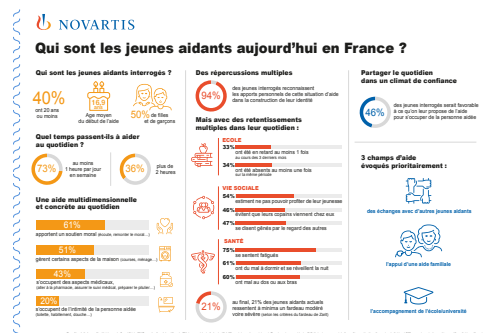
FRANCE

The [National Solidarity Fund for Autonomy](#) (CNSA) is a public establishment created by the law of June 30, 2004. The CNSA has a budget of over 31 billion euros to fulfill its mandate of financing aid for elderly, frail and disabled people, ensuring equal treatment throughout the country and for all disabilities and situations of loss of autonomy. The CNSA ensures a mission of information and network engagement for the elderly, people with disabilities and their families. The CNSA is responsible for expertise and research on issues related to access to autonomy, whatever the age and origin of the disability. The CNSA convenes a group of stakeholders from each of the 101 departments across France, referred to as the '[conference of funders for the prevention of the loss of autonomy of the elderly](#)', to set strategy and determine funding priorities and details for its various interests.

YOUNG CAREGIVERS

A [young caregiver](#) is a child, adolescent or young adult under the age of 25 who comes to the aid, on a regular and frequent basis, of a member of their close entourage who is sick, disabled or dependent. This regular help can be provided on a permanent or non-permanent basis and take several forms, including nursing, care, accompaniment during journeys, administrative procedures, communication, domestic activities, coordination, permanent vigilance and psychological support.

A 2017 study by Novartis-Ipsos, [Who are the young caregivers in France today?](#), examined the impact of the caregiving role on young caregivers' school life and relationships with their peers, and the psychological and physical impact of this situation.



The [French Association of Caregivers](#) has an expert group specific to young caregivers and offers regular, and on-demand, seminars consisting of theory, case studies, workshops and discussion, to educate professionals about the needs of young caregivers. The [JAID project](#), 'Research on Young Helpers' aims to develop research on young caregivers in France.

The [National Association for Young Caregivers](#) (JADE) was created in 2016 to promote the emergence of innovative responses to the needs of young caregivers, and their family caregivers, for visibility and recognition of their situation. The Association implements support measures, develops awareness and encourages actions.



OPPORTUNITIES The COVID-19 crisis has reinforced the role of close caregivers, however greater awareness is required. A cross-sectoral policy that broadly considers the needs of caregivers regardless of the situation of dependency is required. The mindset of the population needs to change in order to facilitate life for caregivers.

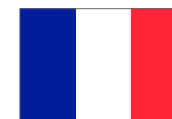
As outlined in a recent [report](#) by the CIAFF ([Collectif Inter-Associatif des Aidants Familiaux](#)), caregivers have been significantly impacted by the period of confinement at home and with reduced supports due to the COVID-19 health crisis. The report calls for national solidarity for recognition of the help and support that caregivers have provided to their children, spouses or parents.

With the creation of the fifth branch of social security ([Organic law n2020-991 Relating to social debt and autonomy](#)) addressing the risk of loss of autonomy, there is a means to bring together and consider policy for caregivers of the elderly and of people with disabilities within the single entity.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



FRANCE

BENEFITS & ALLOWANCE

In France, benefits and allowance are comprehensively described as social action. Social action is one of the components of social protection, alongside social security and provident funds. It encompasses all the actions undertaken by a public authority (municipality, department, state, social security funds) to improve the lives of the inhabitants.

Close caregivers receive indirect financial support through the [personalized independence allowance \(APA\)](#) to partly cover care recipient expenses to ensure their autonomy, and/or to support the needs of people with a disability. The care recipient does not need to reimburse the caregiver with these funds and as a result there is increased advocacy for an allowance specifically for the caregiver.

On December 31, 2017, there were 1,300,000 people over the age of 60 who received the APA dependency benefit. (DREES, dans Études et Résultats, n°1082, d'octobre 2018)

[APA at Home](#) helps pay for the expenses necessary to stay at home (particularly for respite), such as home help services, equipment, hygiene supplies and home improvement work. The application is made locally within the Department and in some cases can be completed online.

[The disability compensation benefit \(PCH\)](#) is intended for people with disabilities who meet specific criteria. These include place of residence, age (up to 60 years) and permanent disability.

The compensation is individualised to the needs of the person and covers all costs associated with the disability, including caregiver support, technical aids, home modifications, transportation and/or vehicle modifications.

In December 2015, 183,000 people received financial assistance under the handicap compensation benefit (PCH). These beneficiaries 'paid' in December 2015 represent nearly 70% of the 271,000 people we are eligible for PCH in France as of December 31, 2015.

[LEARN MORE](#)

The Daily Caregiver Allowance and Daily Parental Allowance as outlined in legislation, [Decree n ° 2020-1208 of 1 October 2020 relating to the daily caregiver allowance and the daily parental presence allowance](#) articulates the procedures for implementing 66 days of paid leave and for payment by the organisations responsible for family benefits. It also provides for similar management of the daily allowances for parental presence allocated to people providing regular assistance to a dependent, sick or disabled relative.

PENSION CREDITS

Close caregivers who have stopped working to look after a child or an adult with a disability in the family home can benefit, under certain conditions, from the old-age insurance of a family caregiver, which guarantees continuity in pension rights. They can also benefit from an extension of the term of the old-age insurance. Informal caregivers may be able to claim a full pension from age 65 instead of age 67. As of October 2020, caregiver leave compensated for retirement rights will be taken into account automatically, without formal application required.



OPPORTUNITIES

The postponement of the pension system until 2021 due to COVID-19 will enable more advocacy about the value of the caregiver contribution to the avoidance of health system utilisation. The importance of the caregiver contribution requires continued attention.

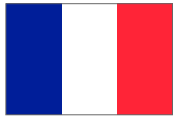
There needs to be neutral policy that does not distinguish caregiving by the needs of the people for whom care is provided. The recent daily caregiver allowance has restrictive conditions: it is strictly reserved for elderly and disabled persons. Persons with long-term illness, such as cancer, are not included.

As new rights are created legally, the mindset of the population has to change to acknowledge caregiver rights. Simplifying administrative procedures at all levels of government would help caregivers access the benefits to which they are entitled.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



FRANCE

WORK & CARE

As of October 2020, France has fulfilled many of the obligations of the 2019 European Parliament Directive on the [Work-Life Balance for Parents and Carers](#). The full implementation must be completed by 2022.

[Family Solidarity Leave](#) allows the employee or self-employed person to assist a seriously ill loved one for a period of three months, renewable once to a maximum period of six months. This leave is not remunerated by the employer, but Health Insurance can pay a daily allowance to support a person at the end of life for 21 days of the leave.

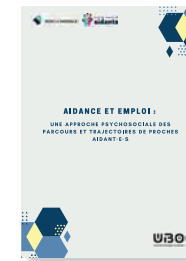
[Caregiver Leave](#) provides employees (private sector and civil servants), self-employed persons and job-seekers with up to three months (66 days) of paid caregiver leave, and they can be off for a total of 365 days over the course of their careers. Leaves can be for partial days and for extended or multiple periods. The caregiver leave is not factored into the calculation of unemployment rights to avoid a reduction in benefits. As of October 2020, the allowance is set at 43.83 euros per day for people living as a couple and 52.08 euros per day for a single person. Payments are by the family allowance funds and the MSA (a specific social security scheme for farmers).

The Caregiver Strategy directs that the 'social branch' negotiation (representative labour unions and employer organisations) include discussion on informal caregivers in the workplace as a compulsory component of corporate social responsibility. These negotiations influence private sector companies which, for competitive reasons, aim to keep their employees on par with the social branch.

[Aid and Employment: a psychosocial approach to the careers and trajectories of caregivers](#), published in 2020, is a qualitative caregiver study to capture perspectives on caregiver situations in order to increase awareness and improve public policy and practice. The goal ultimately is to create an environment where caregivers are able to make informed choices and not have their work and home life be defined for them.

The first step in 2021 is to conduct workshops to support:

- Caregivers: becoming aware of the experience acquired during caring in a perspective of employment;
- Stakeholders: defining their role in enhancing the skills of close caregivers;
- Recruiters and employers: appreciating the potential of caregivers to maximise the overall performance of organisations.



EDUCATION & CARE

Under the [national caregiver strategy](#) there is a commitment in priority six to ensure that educators are aware of and sensitive to the needs of young caregivers, including accommodating flexible study schedules for students.

A system of [valuation of acquired knowledge and experience](#), VAE, recognises experience as a component of qualifying for a diploma. Anyone, whatever their age, nationality, status and level of training, who can demonstrate at least one year of experience directly related to the certification concerned, can apply for the VAE. This certification, which can be a diploma, a title or a professional qualification certificate, must be registered in the National Directory of Professional Certifications (RNCP). VAE helps facilitate reintegration in the labour market, and for family caregivers, it could be a path into the health care sector. However, it is important to recognise that people who are a caregiver to a family member may not want to embark on a career in caregiving.



OPPORTUNITIES

Support caregivers and employers to understand the caregiver's leave and to develop a consistent process for requesting time off for caregiving.

Align caregiver leaves, which can be up to a year, to the paid time off.

Ensure teachers, health and medico-social professionals need to be better informed about the needs of young caregivers and equipped to support, recognise and respond to needs and assist with transitions.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



FRANCE

WELFARE & HEALTH

The complexity of care recipient health situations and caregivers has been an impetus for coordination in the territories. There are also long consultations (three hours) for patients with neurodegenerative diseases (such as Alzheimer's, Parkinson's or multiple sclerosis). The visit allows for a thorough assessment of close caregivers, in addition to, and yet separate from, the assessment and care of the patient. This is vital to understanding the needs of the caregiver and proactively intervening.

In therapeutic patient education programmes, health professionals include components that address the needs of caregivers in order to sustain and enhance their ability to contribute effectively.

By 2022, there will be a single point of contact integrating the PTA, the MAIA and the Réseau for complex health and life trajectories—les dispositifs d'appui à la coordination (DAC).

- [The PTA, plateformes territoriales d'appui](#), provides support, at the request of a general practitioner, for people with complex health issues. The needs of the patient drive the structure of support such that the professionals organise themselves to respond effectively. They establish an appropriate mix of services, and provide system coordination and support that extends to the family caregiver.
- The MAIA ([Méthode d'Action pour l'Intégration des services d'aide et de soins dans le champ de l'Autonomie](#)), reinforced by the ASV law of 2015, has a goal of improving support for people aged 60 and over with loss of autonomy, in order to encourage them to stay at home.

- Health networks (Les réseaux de santé) are multidisciplinary groupings of health professionals (doctors, nurses) and other professionals (social workers, administrative staff, etc.).

In September 2020, there were 118 [DAC](#) in France providing integrated and coordinated health and social support to people with complex needs and their close caregivers.

The 2015 law on the adaptation of society to ageing created a framework for developing inclusive housing providing for grouped or shared accommodation to enable people who have lost their independence due to age, illness or disability to remain in the community.

Housing

Shared accommodation provides residents with private space and shared common areas to promote socialization. The accommodations may be with people with similar conditions, or with a family or a younger person.

This inclusive housing model developed as a grassroots movement supported by various associations, including [Familles Solidaires](#) and [Les Aidants Concepteurs d'Habitats Partagés et Accompagnés](#). In 2018, in partnership with AG2R LA MONDIALE, seven housing projects were opened.

In February 2021, the government announced that 600 inclusive housing units will be built across France over two years.

RESPIRE CARE

Respite for caregivers is linked to the well-being of both the close caregiver and the care recipient. There are several forms of respite: care recipient support at home, or in an establishment; short-term or long-term respite; and respite as a holiday with or without the care recipient.

A right to respite was introduced in the 2015 [law on adapting society to ageing](#). Financial support for respite is strictly reserved for elderly people with strong loss of autonomy who choose to hire caregivers. Funding is modest with an obligation to repay the government for a portion of the funds, which can impose obligation on inheritors.

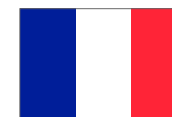
The [national caregiver strategy](#) identifies the need for respite and support to avoid exhaustion. An investment of more than 105 million euros between 2020 and 2022 has been made in order to double available respite across the country.

Education, Support and Short-Term Respite

The support and respite platforms were created to support caregivers of persons with a loss of autonomy. Originally the focus was on day-to-day support of those suffering from Alzheimer's disease. Since then, they have extended their support to all caregivers of elderly persons with a loss of autonomy, regardless of their illness. There are now more than 100 support and respite platforms in France.



HEALTH & WELL-BEING (CONT)



FRANCE

Each support and respite platform offers its own range of services to close caregivers, including:

- training sessions on self-care and accessing support;
- respite care at home for half a day or more to allow the family member to be away;
- accessing support from the medico-social structure, for example, caregiver- and care recipient-specific temporary accommodation, or day care services;
- cultural or social outings that allow the elderly person and their loved one to share a good time together and meet other people;
- networking groups for caregivers; and/or
- psychological counselling.

[LEARN MORE](#)

Day respite is primarily for older people with Alzheimer's or related dementias. Certain day care centres are for people with other neurodegenerative diseases such as Parkinson's disease or older people with a loss of physical autonomy. Day respite is also available for people who have autism.

Day respite is offered by independent structures or by EHPAD (accommodation establishments for dependent elderly people), which develop this particular service in a dedicated space in addition to their main activity. Most day respite programmes provide structured activities to promote well-being and offer full-day or half-day attendance. The per diem cost is set annually by the departmental council. APA at Home can be used to help fund day care. The cost can also be partially financed by the pension fund or insurance, and some municipalities support it through extra legal aid.

Respite at Home

A new pilot programme, 'relaying', has been authorized by the [Direction Générale de la Cohésion Sociale](#) (DGCS) as a three-year experiment (2019–2021). Based on Baluchonage®, relaying is an innovative solution for long-term respite at home: a specialised guide replaces the caregiver at home for several (up to six) consecutive days (24 hours a day), taking care of the person being helped in order to allow the caregiver to benefit from a period of respite. At the end of the assignment, the professional writes an Accompaniment Journal to support the caregiver and offer them intervention strategies adapted to lead their situation. There are 73 of these projects underway, experimented by socio-medical structures with 'voluntary workers'.

By 2021, rules will be developed to address issues of salary, tax obligations, employment status and the establishment of contracts that are fair to all parties. Consideration will also be given to training, supervision and ongoing evaluation of the programme should it be adopted.

Programmes such as [Baluchon France](#) and [Bulle d'air](#) are home respite services for caregivers. They allow the care recipient to remain safe at home where they are most comfortable. To ensure the quality of service, and in partnership with training institutes, the service organises targeted training for service workers to maintain and develop their skills. Educational costs, as well as compensation for relay runners, are covered by AGEFOS PME, the leading network for managing vocational training funds in France. Costs vary according to care recipient need and are partially offset by existing entitlements.

Respite in Institutions

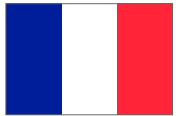
Created in 2013, the [France Répit Foundation](#) has three main objectives: creation of establishments and respite services for families caring for sick, disabled or elderly relatives at home; development of scientific activities around respite; and promotion of respite and support for informal caregivers among people in the health, medico-social and media world.

The [VRF association](#) was created in 2013 in partnership with [PRO BTP](#) (an organisation for the French construction industry) and the [AFM-Téléthon](#) (French Association against Myopathies). The purpose is to provide respite vacations to caregivers and care recipients in a safe and leisurely environment.

[GRATH](#) (Reflection Group and Network for the Temporary Home [Respite] of People with Disabilities) is an association created in 1997 by professionals and parents with the aim of developing temporary respite solutions. The organisation promotes specialized temporary respite packages and respite packages for people of all ages with disabilities or chronic disabling diseases.



HEALTH & WELL-BEING (CONT)



FRANCE

EMOTIONAL & SOCIAL SUPPORT

A support line for people with disabilities and for caregivers was created in 2020 as one of the recommendations arising from the national strategy for family caregivers and in response to the isolation imposed by COVID-19. [Lescommunautés 360](#) is an initiative by government to have 'wrap around', collaborative access and support with all stakeholders (provider, government, associations) who are committed to working seamlessly as one team to support people with disabilities. Callers are referred to regional teams, lescommunautes360, for information and support. Currently there are 86 active lescommunautes360. [LEARN MORE](#)

A [Memory Bistro](#) is a resource space for people living with memory disorders and their carers, located in a public place, usually a café. There are 54 Bistros in France.

[Avec nos proches](#): This listening and information line is open 7 days a week from 8 am to 10 pm. Created in 2012, the service has expanded to a website with information and resources and to advocacy on behalf of caregivers.



Café des Aidants®

[Cafés des Aidants](#) are places, times and information spaces intended for all caregivers, regardless of the age and pathology of their loved one. The meetings take place once a month and are co-facilitated by a social worker and a psychologist with expertise in the issue of caregivers. At each meeting, a theme is proposed to initiate discussions. The aim is to provide support, exchange ideas and meet other caregivers in a friendly setting. The concept has expanded to an online platform. [LEARN MORE](#)



OPPORTUNITIES

Increase awareness of respite options and establish equitable access to respite between the local areas regardless of the caring situation.

Improve the number of respite places, and determine a reasonable balance of publicly funded and privately funded respite. Staffing for health and in-home help needs to be addressed to provide better caregiver support at home.

Adopt the three-hour in-home visit (long visit) permitted by attending physicians of people with chronic neurodegenerative disease to care recipients with any condition in order to better support close caregivers.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



FRANCE

The [CNSA](#) (National Solidarity Fund for Autonomy) runs the the [national portal for information and guidance for elderly people with loss of autonomy and their families](#). Created in 2015, the portal ensures consistent information across the country and provides reliable, quality and easy-to-understand information on support, procedures and offerings of establishments and services.

The [Maison Départementale de l'Autonomie](#) is a single place where older people and people with disabilities can access information on the schemes that concern them. They replace some of the former CLIC local information and coordination centres and MDPH departmental centres for the disabled (the CNSA's accreditation was made possible by the 2015 law on support for the elderly). In some Maison Départementale de l'Autonomie, it is possible to submit applications for autonomy assistance benefits.

A network of 600 [CLICs](#) (Local Information and Coordination Centres) provide information and counselling for older people and their families through a team of gerontologists and home care coordinators. Referrals are welcomed from the elderly person, their family, social services, the attending physician, or a medico-social or hospital structure. Services are offered free of charge and are confidential and personalised. [LEARN](#)

[MORE](#)

Various associations offer training, including [France Alzheimer](#), [Alliance Maladies Rares](#), [UNAFAM](#), [France Parkinson](#), [France AVC](#), the [Ligue contre le Cancer](#), [APF](#), [AFSEP](#), [UNAPEI](#) and [UNAF](#), among others. With COVID-19, a lot of programming has moved online.

Other resources such as [métropole aidante](#), which is local to Lyons, is a three-year experimental project designed to create an inventory of stakeholders serving close caregivers.

SOCIAL PROTECTION RESOURCES

[Ma boussole](#) (my compass) is a social enterprise striving to leverage the public and private sectors, associations and medico-psycho-social companies for the benefit of caregivers. The site is designed to provide caregivers with a personalised response to their support needs, including access to respite and support to balance their personal and professional life. The resource is staffed with people from disease-based associations, the facilities sector and social workers.

[Aidons les nôtres](#) is a community portal for caregivers funded by [AG2R LA MONDIALE](#). The portal provides access to articles by a network of experts. The financial support of AG2R LA MONDIALE also allows the site to be completely free, and to be free of any advertising.

[Essential autonomie](#) is a comprehensive web-based directory of information for caregivers and services specific to the support of caregivers.



OPPORTUNITIES

The COVID-19 crisis has exacerbated the dysfunctions and inequalities of everyday life, including physical and digital separation. Those who experience both are seriously compromised in their ability to access information and other people. There is a need to support people without online access to education and training through the provision of internet access and portable devices, and to help people establish meaningful connections.

The French Association of Caregivers is testing a Young Caregiver Workshop, co-facilitated by a professional in the requisite field of expertise as well as a psychologist, to co-lead three 3-hour workshops. The plan is to provide opportunities for sharing and meeting between young caregivers. The limited number of participants per group will enable more open discussions in a confidential setting. The Workshop has not been implemented as of yet because of COVID-19 related restrictions.

INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN FRANCE

Online Caregiver Training. Building on the 'Cafés des Aidants' concept, the French Association of Caregivers has expanded the caregiver training and socialisation programme to an online platform, which launched in 2017. Both formats were developed with support from [CNSA](#) and [AG2R LA MONDIALE](#), and both share similar objectives of providing caregivers with the space to talk, share and socialize in an informal and friendly setting.

The [Online Caregiver Training](#) includes six 30-minute modules that aim to provide caregivers with tools to understand the condition of the person for whom they are caring, and to learn about how to find help and access local resources. Through these modules, caregivers can improve their understanding and knowledge of caring, develop coping strategies and increase their tolerance and self-esteem so they are less susceptible to burnout.

The most popular modules were on the limits of the caring role; conciliation; and the relationship with one's loved one.

Year 1 evaluation results were impressive.



153 respondent caregivers rated the programme **7.80/10** for substance, form and technique

91% of respondents would recommend the online training to a caregiver

76% of respondent wanted to continue the programme

67% of caregivers felt better able to act and make decisions

To date, approximately **1,865** caregivers have enrolled

Currently there are **11,000+** annual visits to the site with **2,000+** enrollments to the programme



The **French Association of Caregivers** (formed in 2003) advocates for the recognition of the role of caregivers, working with public authorities and representative bodies to address caregiver-related issues, directly support caregivers with *café des aidants*, and promote best practices in caregiving.

Special thanks to the following individuals at the French Association of Caregivers who provided expertise, answered questions and participated in the review:

- Clémentine Cabrières, Directrice
- Gwenaelle Thual, Présidente

SOURCES:

- Anaëlle Cappellari (dir.), *La reconnaissance des proches aidants : regards franco-suisses et pluridisciplinaires*, Presses universitaires d'Aix-Marseille, 2020, Collection du centre de droit social, 431 p.
- French Association of Caregivers. *Retirement for Caregivers*. Page 1. [Accessed: Sept 2020].
- Government of France. (2019) News. *Aidants: une nouvelle stratégie de soutien* [Accessed: Oct 2020]
- Isabelle Robineau. Les aidants familiaux : de leur reconnaissance à la fraternité. Philosophie. Université Paris-Est, 2018. Français. <NNT : 2018PESC0037>.
- Olivier Giraud. *La monétarisation de l'aide apportée par des proches : clivages éthiques et tensions identitaires*

In Germany, the term ‘informal caregiver’ is most frequently used. Informal caregivers are people who provide non-professional home care to a person in need of long-term care due to a physical, mental or emotional illness or disability.

POPULATION DENSITY..... 240 per sq km*
POPULATION URBAN 76.3%*
MEDIAN AGE 46 years**
TOTAL DEPENDENCY RATIO..... 55.4***

* [Worldometer](#)

** [Eurostat 2019](#)

*** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64) in 2020.
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



GERMANY

4,927,000¹ CARERS

5-6%² OF POPULATION

¹ [DIW Berlin](#) calculation (2001 to 2012) – see endnote reference 1

² German Institute for Economic Research, DIW Berlin



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



GERMANY

LEGISLATION

Informal caregivers are defined in the [Social Code-Book XI-Social Care](#), May 1994. The Act (section 19) states that caregivers are people who provide non-professional home care to a person in need of long-term care due to a physical, mental or emotional illness or disability. In addition, the Act grants specific social protection rights to caregivers who provide at least 14 hours of care per week to a care-dependent person.

Long-term care insurance was introduced in Germany in 1995 as the fifth pillar of the social security system ([Social Code Book, Part XI](#) long-term care insurance – SGB XI). Since 2009, insurance has been mandatory for every citizen.

The [First Long-Term Care Strengthening Act](#) (Pflegestärkungsgesetze – PSG I), which came into effect on January 1, 2015, improved support for informal caregivers by giving them access to free care training and by strengthening pension and unemployment rights. Subsequent acts, [Pflegestärkungsgesetze – PSG II](#) (2015), renewed the dependency definition, updated the appraisal method used by the Medical Service of Health Insurance (MDK) and created five new care levels. [Pflegestärkungsgesetze – PSG III](#) (2017) shifted the role of managing and coordinating the advisory services for people in need of care and their relatives (informal caregivers) to the municipalities.

New regulations in 2015 to the [Care Leave Act, 2008/Pflegezeitgesetz](#) built on the foundations of previous laws. Among the changes introduced by the law, the definition of a ‘close family relation’ was expanded to include grandparents, parents, in-laws, step-parents, spouses, civil partners, siblings, children (including adopted or fostered) and grandchildren.

RECOGNITION

There is no National Caregiver Day or Week in Germany. German associations including [Wir Pflegen](#) participated in the European Carers Day on October 6, 2020, noting that the day raised a new awareness of caring relatives in Europe and also in Germany.

YOUNG CARERS

Young carers are young people up to 18 years of age who support one person—or more—to whom they feel connected and/or committed, over a long period of time. Significant care obligations occur when the care recipient is dependent on support due to mental and physical illness, impairment, addiction or age-related change. In doing so, they assume a high level of responsibility that is normally associated with adults.

[Jump Young Carers](#) is a working group tasked with drawing attention to young carers in different life situations and to sensitise institutions to support this target group. In addition to specialists from the education, social and health sectors, young adult carers and former young carers and young adult carers are also active in the group.



IACO was established
in 2012 to build
awareness and
recognition of carers
around the world.

[LEARN MORE](#)

OPPORTUNITIES



Address stigma toward informal caregiving for older individuals in particular through knowledge and awareness.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



GERMANY

ALLOWANCE

There is no direct state-/government-issued financial support for informal caregivers. The German government provides either a care allowance or home care in-kind to the dependent person through long-term care insurance.

The [care allowance](#) is a financial benefit from the [long-term care insurance](#) (LTCI) paid to the care recipient who can pass the money on to family caregivers as financial recognition. The amount of the care allowance depends on a person's degree of [care requirements](#): Level 1 is the lowest level of need for care, such as those with a slight impairment to independence; Level 5 is for those with severe impairment of independence. The care recipient must be receiving care in a suitable home environment by a relative or volunteer caregiver.

An increase in the care allowance and changes to the benefits of the LTCI are expected in 2021 as outlined in Social Code Book XI.

The care allowance can also be used to fund migrant caregivers (e.g., from Eastern EU countries); this applies especially to 24-hour care. Legal recruitment occurs through agencies in Germany and in the posting country. Migrant 24-hour caregivers are the employees of a service agency, for example in Poland, and have to be paid privately; they are not under contract to the long-term care insurance fund. It is also

possible to only make partial use of the care services and aids provided and paid for by the insurance company, and instead organise part of the care oneself. In addition to the pro-rata care benefits in kind, the long-term care insurance fund pays a proportionate care allowance ([combined service](#)). [LEARN MORE](#)

Special allowances are available to pay for the cost of modifying the home to accommodate nursing care needs. A maximum of €4,000 can be granted for each project if there are no other means of financing. People classified as Care Level 0 who face considerable restrictions in their everyday activities may also receive this allowance.

The long-term care allowance is not deemed to be 'income'. It is free of taxes and contributions so that working caregivers (regularly part-time) can simply add it to their net income. The care allowance is also not taken into account in the means test for social assistance.

[Additional care and relief services](#) (§45b SGB XI) are provided as a flat rate, regardless of the dependent person's level of care, for those who receive care at home. Funding is paid for services such as day and night care, short-term care and prevention care.

PENSIONS

The care allowance does not impact pension income.

LTCI will pay contributions toward statutory pension insurance in line with §44 SGB XI for informal caregivers providing personal or domestic help or long-term care of at least 14 hours per week. The level of contributions is based on the number of care hours per week and the care level. The caregiver may not, however, be employed more than 30 hours per week as they would otherwise be liable to pay social security contributions. [LEARN MORE](#)

Under certain conditions, the long-term care insurance of the person in need of care will cover the contributions to the social pension insurance (SPI) for the caregiver. To comply with the eligibility criteria, informal caregivers must nevertheless provide at least 14 hours of care per week and:

- live in a European Economic Area or in Switzerland;
- care for at least 60 days per year;
- not be gainfully employed for more than 30 hours per week; and
- not benefit from a full old-age pension.

Since January 1, 2013, informal care provided to more than one beneficiary can be added up to meet the 14-hour-per-week criteria. [LEARN MORE](#) (page 107)





WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



GERMANY

WORK & CARE

As of 2008, a person who provides home care to a close relative assessed at not less than Care Level I (minor impairments of autonomy or of skills) has the right to a carer's leave. This consists of an unpaid leave from work of up to six months with continued social insurance coverage ([Care Leave Act, 2008/Pflegezeitgesetz](#)). The leave is only a requirement in companies that employ more than 15 people. The employer has to be notified in writing at least ten days before the beginning of the leave, including information about the dates and duration of the leave. Workers are provided with up to ten paid days off to organise care for a close relative with a sudden need for caregiving support. [READ MORE](#)

In January 2012, new legislation targeting employees who provide care at home came into effect ([Family Care Leave Act/Familienpflegezeitgesetz - FPfZG](#)). The legislation permits employees to reduce their working hours—in agreement with their employer—to a minimum of 15 hours per week over a maximum duration of two years.

The Caregiver Leave Act (Pflegezeitgesetz, 2008) and Family Caregiver Leave Act (Familienpflegezeitgesetz, 2012) were further enhanced in 2015 under the [Law on the 'better reconciliation of family, work and long-term care'](#) (Gesetz zur besseren Vereinbarkeit von Familie, Pflege und Beruf). These together provide the legal framework for Germany's current care leave policies, including:

- a right to partial leave of absence for up to 24 months if the worker is looking after a close relative requiring long-term care in the home environment;

- wage compensation for acute care leave of up to ten days (typically 90% of net earnings) through long-term care insurance in the form of 'Pflegeunterstützungsgeld' or 'care support payments';
- family care leave available for those providing care for minors living outside the home (such as in institutional facilities); and
- leave of up to three months for people supporting family members at the end of life.

Employees taking a partial leave or reduced work hours can top up their reduced salary by half of the difference between the old and the new lower salary with an interest-free state loan from the [Bundesamt für Familie und gesellschaftliche Aufgaben \(BAFzA\)/Federal Department for Family and Civil Society Affairs](#). Following the caregiving period, the employee has to work full-time until the credit is paid back.

As an EU Member State, Germany is due to implement the carers' rights introduced by the now-approved [Directive on the Work-Life Balance for Parents and Carers](#), which covers caregiver leave and flexible working arrangements. While the German system includes good leave entitlements for caregivers and already complies with the requirements of the Directive, the ability to access flexible working arrangements often remains a challenge for working caregivers due to cultural barriers and employers' reluctance.

OPPORTUNITIES



While financial support for leave exceeding a ten-day period is not provided through the long-term care insurance system, carers may apply directly to the BAFzA for an interest-free loan providing monthly payments covering half of the net earnings foregone due to reduced working hours. Although it represents a substantial achievement in improving the social protection of informal carers, the Care Leave Act of 2015 ultimately still shifts costs to persons providing lengthier periods of care for family members. (Schneekloth et al.)

The uptake of the caregiver leaves outlined in the 2015 Act for a Better Reconciliation of Family, Care and Work Law on the 'better reconciliation of family, work and long-term care' has been low. This is due to the obligation to repay the loan and the restrictive legal entitlement of the benefit to employees of companies with more than 15 employees only (or 25 in the case of a part-time carer's leave), which limits those who qualify.

The accrual of pension credits for the time spent caring, which is available to caregivers under certain circumstances, should be open to those who already receive a full old-age pension.



WORK & EDUCATION (CONT.)



GERMANY

EDUCATION & CARE

In contrast to a growing body of research on the situation of adult family caregivers, in Germany little is known about the specific situations and needs of young caregivers. They are not recognised as such in the health or social sector, nor in education. (Leu et al)

The first prevalence study of young caregivers in 2016 estimated that 5% of children aged 12 to 17 years were young caregivers. (Lux et al)

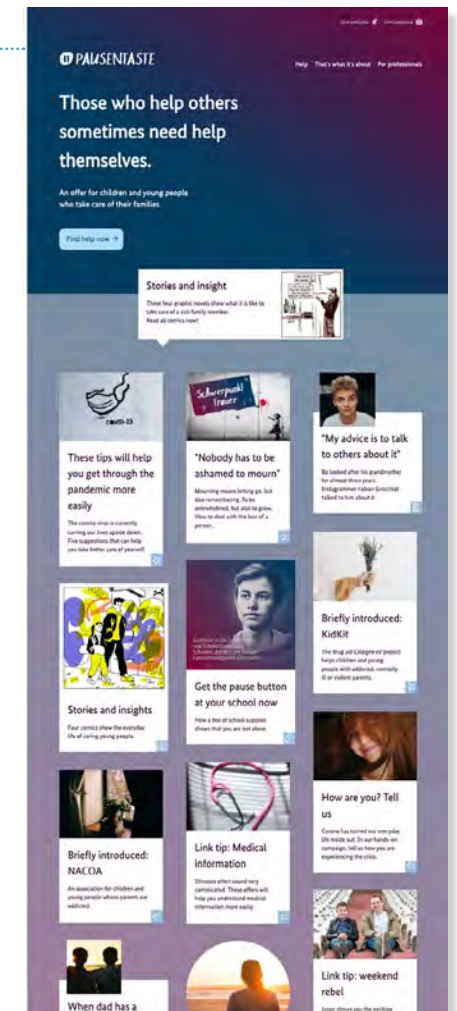
The [young-carer friendly school](#) concept is designed to support teachers and students to become sensitive to the needs of students who are also carers.

According to a study by the University of Witten-Herdecke (2018) on behalf of the Federal Ministry of Health, around 479,000 children and young people across Germany look after relatives who are chronically ill or in need of care. They help with a wide variety of tasks, including cooking, shopping and cleaning. Sometimes, they also take on significant nursing tasks. Many are very worried about their relatives in need of care and assistance, have too little free time apart from school and care, are involved in physically-demanding tasks and have no one to talk about their situation.



In January 2018, the project [Pausentaste](#)—‘Those who help others sometimes need help themselves’ was initiated. The BMFSFJ project aims to support young caregivers nationwide through access to basic counselling services. The concept of a ‘pause button’ lends emphasis to the message of breaks from caregiving, reflection and taking advantage of offers of help or to anonymously talk about their own situation. The offer can be accessed via the [Pausentaste](#) website, by phone and by email. In addition, advice is also available via online chat. The site provides resources for professionals, including school materials, publications, technical literature and studies pertaining to young caregivers.

Support is available for further vocational training for caregivers wishing to return to employment in accordance with [Social Security Code \(SGB III\)](#).





HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



GERMANY

RESPIRE CARE

By mandate of the Act to Reorient the Long-term Care Insurance 2012 ([Pflege-Neuaufrichtungs-Gesetz](#)), the German government improved a number of benefits, including the benefits of respite care and short-term residential care for persons receiving care allowance. Short-term, daytime and night-time care were introduced to support caregivers. [READ MORE](#)

Short-term care is subsidized, to a maximum of 56 days per year, through the long-term care insurance fund. It must be provided in a facility. All recognized persons in need of care (Care Levels 2–5) are entitled to short-term care as are people who suddenly need short-term care, due to an illness or an accident.

Preventive care is replacement care for a caregiver in the home for a maximum of six weeks per calendar year generally due to vacation, illness or other reason. [LEARN MORE](#)

The long-term care insurance subsidises the care costs incurred as part of short-term care with a lump sum. All other costs for short-term care must be paid by those in need of care out of their own pocket. If the person in need of care does not have the financial means for these additional costs, the social welfare office steps in or relatives pay the short-term care costs. People receiving the monthly flat sum through [additional care and relief services](#) can use the funds for the costs of accommodation.

Short-term care can be coupled with preventive care, which is provided at home and subsidized for up to six weeks per year. In contrast to short-term care, preventive care is only granted if the caregiver has already been on duty for six months. If the first- and second-degree relatives take care of the preventive care, the care insurance funds pay out a maximum of 1.5 times the care allowance.



EMOTIONAL & SOCIAL

The shortage of care professionals and poor working conditions are contributing factors to the quality of care in Germany. Moreover, there is concern about the quality of care delivered by informal caregivers. As a result LTCI organisations have been required to offer free training courses in LTC for informal caregivers since 2008. People receiving informal LTC are required to make use of counselling services offered by accredited care facilities or counselling centres in order to ensure the quality of such care. Since 2009, informal caregivers have had a legal right to care counselling by specially qualified care advisers through the long-term care insurance funds. [LEARN MORE](#)



Caregivers providing care to a person with a minimum nursing Care Level 2 are insured against accidents under the statutory accident insurance. Coverage is accessed through the care recipients' long-term care insurance regardless of the length of time spent working as a caregiver.

The [Young Carer Help](#) charitable UG (limited liability) is a contact point for children with sick relatives as well as specialist staff who work with children of sick relatives through schools, clubs and advice centres. The Young Carer Help website offers information and practical concepts for the support of young caregivers in schools and communities. Personal individual advice onsite, by telephone or by video conference, offers a professional exchange between therapists, educators and former caregivers. All advisory services are free of charge.

[Young Helping Hands](#) provides education about caring children, young people and young adults. It is the contact point for children and young people with sick relatives, for those previously affected and for interested stakeholders (e.g., specialists from the educational field). In cooperation with other resources for caring children and young people, Young Helping Hands collaborates and advocates on behalf of young caregivers. Young Helping Hands works with other public bodies (e.g., schools, universities) to develop strategies to proactively identify and support young caregivers.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.

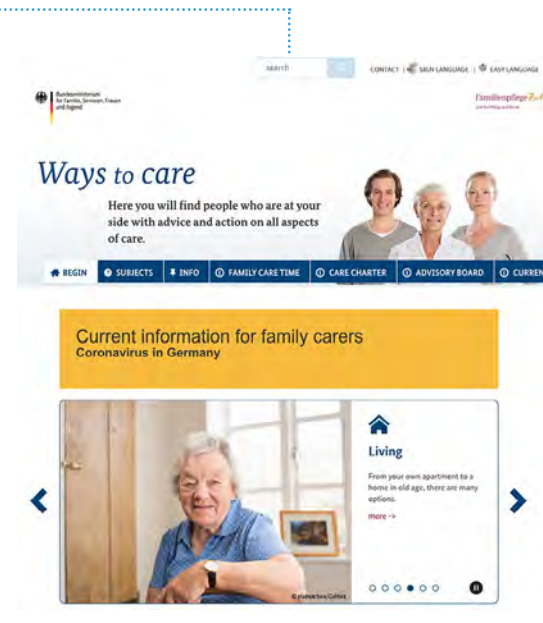


GERMANY

Since 2011, the German Federal Ministry of Family Affairs, Senior Citizens, Women and Youth has hosted an [information website](#) and operated a counselling hotline ([Pflegetelefon](#)) for family caregivers. The website provides information and advice about all aspects of nursing care, including information about the right to benefits, assistance at home, respite and counselling services, among others.

Additionally, 'care support stations' ([Pflegestützpunkte](#)) are set up by the health and care insurance funds at the discretion of the federated states (landers) of which there 16 across Germany. These stations are staffed by care advisers who offer advice and support to those seeking help, whether for themselves or for relatives. The care advisers, usually nurses, have special expertise, in particular in social and social security law, to help people understand their options.

[Care advisers](#) are typically nurses who have knowledge and expertise in the service options available to families and their relative caregivers. They help coordinate the paperwork and procedures to access services. In some communities, the care advisers work at a 'care support point' that enables efficient networking and coordination of services and social service providers.



EDUCATION & TRAINING

Long-term care insurance offers care courses, in groups or individually at home, in which unpaid caregivers can learn practical skills for properly caring for a person and learn about disease-specific care issues. Practical skills include supporting mobilization and positioning, along with advice on nutrition and personal hygiene. Courses also address the fatigue, stress and physical needs of the caregiver.

OPPORTUNITIES



At the peak of the COVID-19 crisis, the government took steps to facilitate family members' caring roles for their (elderly) dependents. Among the changes, the duration of the caregiver's grant, a wage compensation benefit for short-term absence from work to fulfil care obligations, and the accompanying leave provision, were doubled from 10 to 20 work days. In addition, the government made the unpaid family care leave more flexible. Sustaining this practice beyond COVID-19 would be helpful to informal caregivers.



INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN GERMANY

[Wir Pflegen](#) actively contributes to the development of digital self-help tools for caregivers, irrespective of their particular care setting. The national pilot project, 'Online self-help initiatives for caregiving relatives' (OSHI-PA), funded by the Federal Ministry of Health and the Techniker Krankenkasse in NRW, has allowed for the development of a smartphone app—in.kontakt. The app is dedicated to self-help, which includes peer-support groups to strengthen the exchange between caring relatives.

The expansion of virtual self-help gives caregiving relatives and self-help groups the opportunity to exchange, inform and support each other in a protected manner using various technological communication media (e.g., computer, tablet, smartphone) and Internet-based forms of communication (e.g., online portal with video chat, forums and social media).

The test version was presented in October 2018 in Berlin, and the app was made available on all platforms at the beginning of 2019. in.kontakt is free of charge and provides informal carers with access to important information about care and caring, as well as to a community of fellow carers. [LEARN MORE](#)



Wir Pflegen – We Maintain is an advocacy and self-help organization of caring relatives in Germany. Members share a common interest in helping caregivers nationwide, in the federal states and in the municipalities, to secure more rights, to strengthen support in home care, and to improve the care of people in need of care.



Allianz pflegende Angehörige – Alliance of Caring Relatives is an advocacy group representing caregivers of all ages.

Special thank you to Stecy Yghemonos, Executive Director, [Eurocarers](#), for his expertise and review of this chapter.

SOURCES:

- 1. Estimate of the number of carers according to DIW Berlin's calculations for the years 2001 to 2012 on the basis of data from the Socio-Economic Panel Study (SOEP), between 5 and 6% of all adults regularly provide informal care—between 4,106,000 and 4,927,000.
- Eurocarers. Towards carer-friendly societies. [Eurocarers country profiles - Germany](#).
- Eurostat. 2019. [Population:Structure Indicators](#).
- Leu, A & Becker, S. 2017. A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies*, 20 (6), 750–762. ISSN 1367-6261.
- Lux, K. & Eggert, S. (2017). ZQP-Analyse Erfahrungen von Jugendlichen mit Pflegebedürftigkeit in der Familie. In Zentrum für Qualität in der Pflege (ed.). ZQP-Report Junge Pflegende, 1st edn. ZQP: Berlin: 14–25.
- Schneekloth, U., Geiss, S., Pupeter, M., Rothgang, H., Kalwitzki, T. & Müller, R. (2017). Studie zur Wirkung des Pflege-Neuausrichtungs-Gesetzes (PNG) und des ersten Pflegestärkungsgesetzes (PSG I). Abschlussbericht, Bundesministerium für Gesundheit, München: TNS Infratest, Link (Stand: 16.10.2017).
- Zwar, L., Angermeyer, M.C., Matschinger, H., Riedel-Heller, S.G., König, H.H., & Hajek, A. (2020). Public stigma towards informal caregiving in Germany: a descriptive study. *Aging Ment Health*. 29, 1–10. doi: 10.1080/13607863.2020.1758913. Epub ahead of print. PMID: 32347119.

In Hong Kong, the term 'caregiver' is most frequently used. Caregivers are people with family status, which means they have responsibility for the care of an immediate family member.

POPULATION DENSITY..... 6,880 per sq km*
POPULATION URBAN 100%**
MEDIAN AGE 44.6 years***
TOTAL DEPENDENCY RATIO..... 44.7****

* Govt HK, Hong Kong the Facts

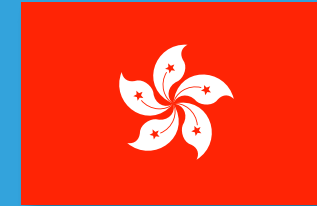
** Worldometer

*** Census and Statistics Department. Hong Kong Population Projections 2020–2069. Hong Kong Special Administrative Region, 2020.

**** Wikipedia

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64).

The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



HONG KONG

375,848¹ CARERS

5%² OF POPULATION

¹ Estimation assuming 5% of the population based on experience in other countries.

² Hong Kong 2020 Population: 7,516,975 (Worldometer)



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



HONG KONG

LEGISLATION

There is no legislation formally recognising and supporting unpaid caregivers.

In 2019, a working group under elderly services of the Hong Kong Council of Social Services submitted a policy framework, [Support for Carers of Elderly Persons and of Persons with Disabilities](#), to the [Legislative Council Committee on Welfare Services](#). The recommendations included the need for formal recognition of caregivers as one of the six prioritized pillars.



[Family Status Discrimination Ordinance](#) (FSDO) was passed in 1997 with a provision to eliminate discrimination on the grounds of family status (i.e., caregiving) and stipulates protection for persons with family status. [LEARN MORE](#)



STUDIES HAVE SHOWN THAT 3 OUT OF 5 PEOPLE WILL HAVE THE OPPORTUNITY TO BECOME "CAREGIVERS" IN THEIR LIFETIME

Am I a caregiver?

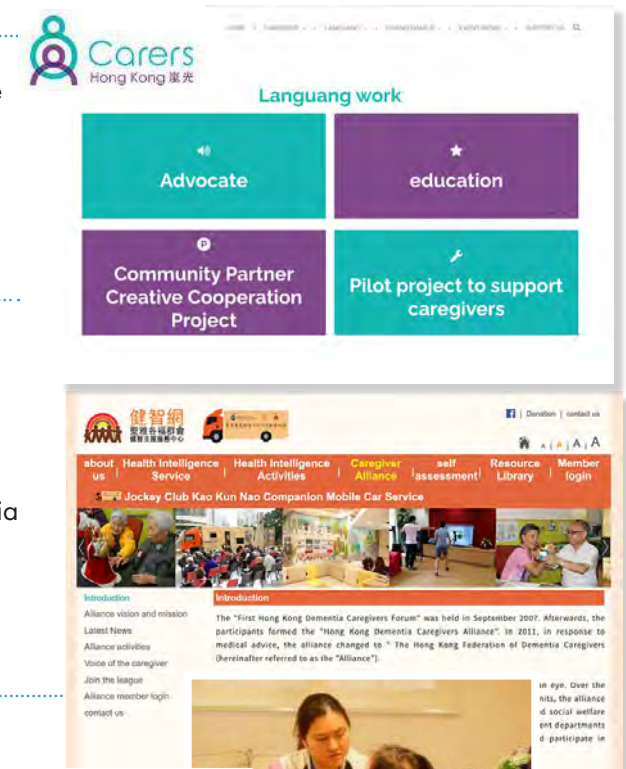
RECOGNITION

The Hong Kong Carers Alliance and [Carers Hong Kong](#) advocate for the third Saturday of October as 'Carer Day' to promote recognition and support for caregivers. Dignitaries and government officials are invited to participate. The first Carer Day Carnival and symposium was held on October 21, 2017, to support caregivers and provide stress relief strategies and resources for their family members.

Several carer organizations have been established in the past decades. In 2017, the Hong Kong Carers Alliance was formed by the Salvation Army Carer Association, the Hong Kong Carer Alliance for People with Dementia, City of Love, Grace Parent Association and The Association of Parents of the Severely Mentally Handicapped. [Hong Kong Carer Alliance for Dementia](#) strives for the protection and realisation of dementia patients' and carers' rights by actively participating in various dementia conferences, holding community exhibitions and networking events.



First Hong Kong Dementia Caregivers Forum



in eye. Over the
nits, the alliance
d social welfare
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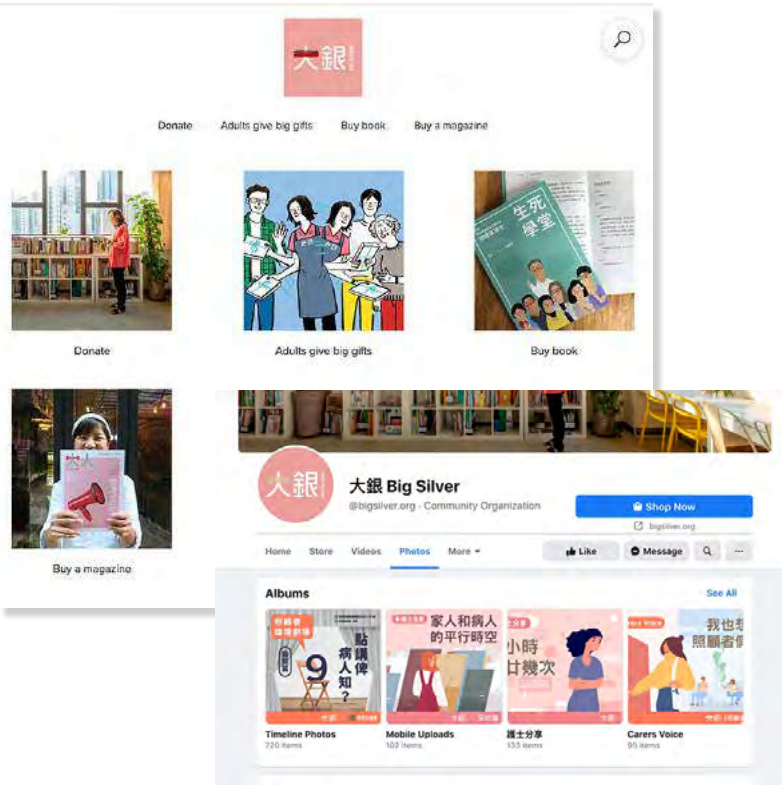


CARER RECOGNITION (CONT.)



HONG KONG

[Big Silver Community](#) is a charity that focusses on the ageing population. It aims to promote an age-friendly community and support caregivers of older adults. It has launched a monthly publication (BIG MAG) and various innovative community activities to establish a social network of older adults, NGOs, corporations, professionals and media.



Carers Voice is one of the innovative activities launched by the Big Silver Community. Carers Voice uses online platforms (e.g., [Facebook](#), [YouTube](#)) to attract the caregivers of patients with dementia and encourage them to express themselves.



The Hong Kong government has launched an initiative to support caregivers by providing training for foreign domestic helpers. The [Pilot Scheme on Training for Foreign Domestic Helpers in Elderly Care](#) is a comprehensive course comprising eight core and four elective modules. This free training has been provided to approximately 950 people between 2019 to 2020 and will continue into 2021.

OPPORTUNITIES



The Hong Kong government has begun to take the lead in enhancing support for caregivers as indicated by the following two actions:

1. The Census and Statistics Department included questions for caregivers in the recent disability survey for the first time in history. The Department has decided to include caregiver statistics as one of the data topics in the upcoming 2021 Population Census.
2. A study on caregiver policy has been launched by Labour and Welfare Bureau (LWB) of the Government of the Hong Kong Special Administrative Region of People's Republic of China and is expected to be completed in mid-2021. The study involves interviewing caregivers of older adults and persons with disabilities, as well as service workers and professionals, to explore the needs of caregivers and develop comprehensive policy recommendations.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



HONG KONG

DIRECT FINANCIAL SUPPORT

Dependent Parent and Dependent Grandparent Allowance can be claimed by Individuals or their spouse (who is residing with the individual) for each dependent parent/grandparent during the year.

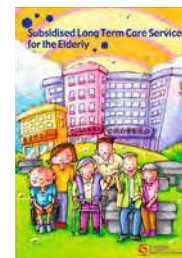


Disabled Dependent Allowance can be claimed by individuals or their spouse if they care for a dependent who is eligible to claim an allowance under the Government's Disability Allowance Scheme.

The Hong Kong Mandatory Provident Fund is Pillar 2 of the Modern Retirement System that does not take informal support into account. Unpaid caregivers therefore do not receive any pension payments for their care work. Only those who participated in the workforce will benefit from certain pension schemes.

The Community Care Fund (CCF), established in 2011, implements assistance programmes on a pilot basis to help the government identify those that can be scaled and offered as regular assistance. The CCF launched a two-year pilot project, the Pilot Scheme on Living Allowance for Carers of Elderly Persons from Low-income Families, in June 2014, to supplement the living expenses of caregivers. The allowance ensures that elderly persons in need of long-term care services can, with the help of their caregivers, receive proper care and be able to age in the community. The allowance is issued monthly based on a self-certified 'Record of Hours of Caregiving' which must be submitted to the service unit on or before the date prescribed, otherwise, the payment of allowance will be deferred. The caregiver applicant for the elderly person(s) must meet all six eligibility criteria:

1. The elderly care recipient must be living in Hong Kong and have been assessed under SWD's Standardised Care Need Assessment Mechanism for Elderly Services (SCNAMES) to be of moderate or severe level of impairment, and have been on the Central Waiting List (CWL) for subsidised long-term care services (i.e., residential care services [RCS] and/or community care services [CCS]) on or before November 30, 2017.
2. The elderly care recipient must be living in the community.
3. The caregiver must be competent to assume the caregiving role and provide at least 80 hours of caregiving work per month, or at least 120 hours per month if caring for more than one eligible elderly person.



4. The caregiver must be a Hong Kong resident living in Hong Kong and not engaged in any form of employment relationship with the elderly care recipient.
5. The caregiver must not be a recipient of Comprehensive Social Security Assistance (CSSA), Old Age Living Allowance (OALA) or other allowance for taking care of the same elderly person under Phase II of the CCF 'Pilot Scheme on Living Allowance for Low-income Carers of Persons with Disabilities'.
6. The caregiver must be from a low-income family with monthly household income, excluding assets, as per the SWD criteria.



Phase II of the Pilot Scheme launched in October 2016 and Phase III in 2020. Phase III continues to provide support to caregivers of older adults and is extended to caregivers of people with disabilities.



FINANCIAL SUPPORT (CONT.)



HONG KONG

INDIRECT FINANCIAL SUPPORT

Older adults may be financially dependent on caregivers whose financial burden is relieved by supporting older adults' housing needs. The [Housing Authority](#) provides two main types of housing for older adults in public rental estates: Housing for Senior Citizens Units and Self-Contained Small Flats.



[Compassionate rehousing](#) is a form of special housing assistance to individuals and families who have urgent and long-term housing needs due to social and medical needs under special circumstances, and have no other feasible solutions to their housing problems.

[Elderly Health Care Voucher Scheme](#) was launched in 2009 to offer an annual voucher amount of HK\$2,000 to older adults aged 65 or older, with an accumulation limit of HK\$8,000 to use for private healthcare services and not for family caregivers.



IACO has established 6 guiding principles to improve carers' lives across the globe:

- 1: Recognition
- 2: Equal Opportunities
- 3: Information and Knowledge
- 4: Health and Well-Being
- 5: Employment
- 6: Financial Security



OPPORTUNITIES



There are many eligibility restrictions for the financial support measures listed. A review of caregiver allowance policy was included as one of the key objectives under the consultancy study, by the Sau Po Centre on Ageing, on the pilot schemes on living allowance for low-income carers of persons with disabilities and elderly persons from low-income families (unpublished). This information will help the government work on improving financial support for caregivers.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



HONG KONG

WORK & CARE

[Family Status Discrimination Ordinance](#) (FSDO) expressly prohibits discrimination toward a person on the basis of family status (i.e., caregiving for an immediate family member), which covers different areas, including employment.

The [Equal Opportunities Commission](#) (EOC) has issued a [Code of Practice](#) (the Code) in accordance with the FSDO. The Code is designed to help employees and employers understand their responsibilities and rights under the FSDO. The EOC operates a complaints handling, investigation and conciliation system. Aggrieved persons can also institute civil proceedings independently.

The Labour and Welfare Bureau encourages employers (there is no legislative requirement) to adopt [family-friendly employment practices](#), such as special leaves, flexible work arrangements and living support, to help employees who are balancing work and family responsibilities.

The government launched a labour policy to allow households to employ [foreign domestic helpers](#) in the 1970s. This 'money-for-care' solution allows caregiving responsibilities to be shared so family members can work.



OPPORTUNITIES



Some individual social service organisations and commercial corporations have initiated caregiver leave under their human resources policy. The implementation of workplace accommodative measures is rare in Hong Kong. For formal accommodative measures, compassionate leave is the most common measure reported (30.8%); flexible working hours is the most common discretionary accommodative measure (7.6%). The value of supporting working caregivers needs to be better understood and supportive policies adopted (Lou et al. 2017).

More research is required to understand the prevalence and situation of young carers, along with identifying supportive measures for them.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



HONG KONG

EMOTIONAL & SOCIAL SUPPORT

Carer Support Service aims to facilitate and support caregivers to look after older adults in the community. Most of the community support service units, including District Elderly Caring Centres (DECC), Neighbourhood Elderly Centres (NEC), Day Care Centres/Units for the Elderly (D/E and DCUs), Integrated Home Care Services (IHCS) and Enhanced Home and Community Care Services (EHCCS), provide various kinds of carer support service. There may be an annual membership fee and/or fees for individual programmes which differ for each community support service unit. The scope of service includes:

- skill-training and educational programmes;
- self-help and mutual support groups;
- resource corner;
- simple counselling and referral services;
- information and reference materials relating to the care of elders;
- demonstration/loan of rehabilitation-aid equipment; and
- social and recreational activities.

The Caregiver Support Model & Psycho-education Program on Empowerment: Development and Validation Project is a collaboration of the Simon K. Y. Lee Foundation and the City University of Hong Kong. Deliverables include a Caregiver Needs Assessment tool, personalized Caregiver Intervention Plan Guidelines, a step-by-step Case Monitoring Template, as well as information on caregiver resources and services to support family caregivers. These tools will enable the implementation of a validated Caregiver Support Model as a framework for helping and empowering family caregivers of frail elders, reducing caregiver stress and improving their quality of life.



Caritas Jockey Club Resource and Support Centre for Carers provides a carer support hotline for caregivers.



Hong Kong Federation of Women's Centres cooperates with the Social Welfare Department to deliver a 'Carer Cafe' in 10 locations for caregivers to unwind.



HEALTH & WELL-BEING (CONT)



HONG KONG

RESPIRE CARE

The Social Welfare Department offers a [residential respite service for persons with disabilities](#) and older adults, as well as emergency placement for older adults. There is a service fee for residential respite and a limit on duration. However, older adults occupying emergency placement are exempted from paying service fees for the first three months of their stay.

Residential respite service for older adults: duration of this service is at least 24 hours to no more than six weeks (i.e., 42 days), which is also the maximum accumulative duration of period(s) of use of the service within the 12 months preceding the date of admission for the service. Up to six months advance booking for the designated places for residential respite service is available.

Residential respite service for persons with disabilities: duration of stay should be no more than 14 consecutive days in general. The service can be used repeatedly.

Emergency placement for the elderly: period of stay should not exceed three months, other than very exceptional circumstances for which the referring worker would have to provide justifications as well as a prospective discharge plan.

Respite through day care centres is available for older adults, persons with severe disabilities and young children.

Integrated Home Care Services offer home respite services to older adults, persons with disabilities, and families with social need.

OPPORTUNITIES



40% of working carers of older adults suffer from high burden, depressive symptoms and poor family function at the same time, which calls for support that goes beyond what currently exists (Lou et al. 2019). The long-term need is to develop carer-centred policy with corresponding services to ensure the protection of caregiver rights and to empower them to achieve an optimal balance between self-care and taking care of their family members.

Short- and mid-term measures include the following:

1. Increase public awareness of carers' identity and needs.
2. Enhance accessibility of service information.
3. Develop technology-enhanced services.
4. Pilot an innovative service model to support working caregivers.
5. Promote accommodative measures.
6. Promote work-life integration for caregivers.

Although there are invaluable emotional benefits to providing care, being a carer can be time-consuming and take a heavy toll on the carer's health and well-being.





INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



HONG KONG

Online health-related and service-related information for the general public are offered by government (e.g., Hospital Authority, Social Welfare Department), academics (e.g., [Sau Po Research Centre on Ageing](#)) and NGOs (e.g., Caritas Jockey Club Resource and Support Centre for Carers, [656carer](#)).

[Carer Support Service](#) provides skill-training and educational programmes for carers of older adults.

Non-government organizations (NGOs) also provide education and training to carers of older adults (e.g., [CARE college](#), [SAGE Jockey Club Integrated Transitional Care Programme](#), [Jockey Club All Brilliant Carers Project](#)).

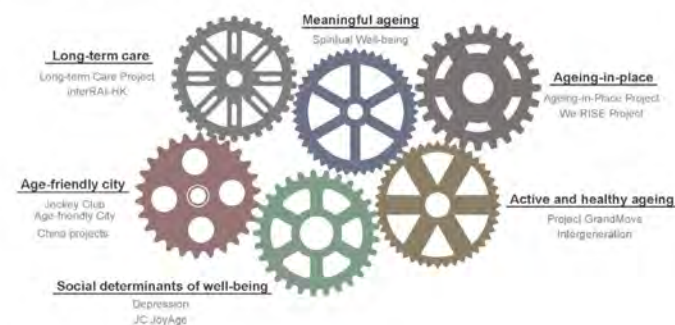
[Sau Po Centre on Ageing](#) conducts a Certificate Course for Caregivers on Behavioural and Psychological Symptoms of Dementia (BPSD) and Dementia Care.



Research by population



Research by themes



OPPORTUNITIES



Information and education/training are available but fragmented, which lowers accessibility. One-stop information platforms are available for carers of older adults (e.g., [WeRISE – Stroke Family Empowerment Project](#), [656carer](#)). However, they are disease specific (e.g., stroke, dementia). It is recommended that a holistic, one-stop information platform be developed to assist different carers with different needs. It is also important to create a learning community to improve caregiver literacy to enable informed decision-making.

INNOVATIVE CARER PRACTICES

Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)



Carers Hong Kong (established in 2018) is advised by caregivers and patients' groups, cross-sectoral professional bodies and NGOs to promote better policies and quality services for caregivers' selfless.

Special thanks to the following individuals at The University of Hong Kong who provided expertise, answered questions and participated in the review of this chapter:

- Dr Vivian Weiqun LOU, Director, Sau Po Centre on Ageing, Associate Professor, Department of Social Work & Social Administration
- Ms Benita Pui Yin CHENG, Research Assistant, Sau Po Centre on Ageing

Increase visibility and
awareness of caregiver issues

Advance action on policy and
programming for carers

Accelerate the spread and
scale of leading carer
practices globally

SOURCES:

- Census and Statistics Department. (2015). [Persons with Disabilities and Chronic Diseases in Hong Kong](#). Hong Kong Special Administrative Region Retrieved on Sept 15.
- Lou, W. Q. V. & Lai, W. L. D. (2017). Financial Impacts of Family Caregiving: An Investigation of the Moderating Effects of Workplace Accommodative Measures and Domestic Helpers. Central Policy Unit.
- Lou, V. W. Q., Chui, E., Fu, Y. Y., Wong, S. B. K., Cheung, E., Leung, R., Cheng, C., Leung, E., Szeto, R., Wong, K., & Choi, B. (2019). Family Caregivers Caring for Community-dwelling Older Adults: Profiles, Well-being and Unmet Needs. Hong Kong: Hong Kong Council of Social Service.



In India, the term 'family caregiver' is most frequently used. Family caregivers are any family members who provide care, support or assistance to a person with a disability, long-term illness or age-related condition.



POPULATION DENSITY..... 464 per sq km*
POPULATION URBAN 35%*
MEDIAN AGE 28.4 years*
TOTAL DEPENDENCY RATIO..... 48.7**

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64) in 2020.
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



INDIA

138,327,941¹ CARERS
10%² OF POPULATION

¹ Estimate based on other country's experiences.

² India 2020 Population: 1,383,279,413 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



INDIA

LEGISLATION

While family caregivers are not formally recognised in India, several pieces of legislation address their responsibilities.

The [Maintenance and Welfare of Parents and Senior Citizens Act, 2007](#), and amended in 2019, states that children are required to care for their parents. The amendments in 2019 broaden the definition of children to include step children, adoptive children, children-in-law and legal guardians of minor children. As caregivers, they are required to look after family members through active care and, if ordered by Maintenance Tribunals, to pay a monthly maintenance amount to parents. Penalties for failure to comply, which include fines and/or imprisonment, have been increased. The Act also establishes requirements for home care, requires hospitals to have facilities for senior citizens and requires the police to establish a special unit for senior citizens in every district (there are 718 districts in India). The exemptions for the regions of Jammu and Kashmir in the 2007 version of the Act have been removed.

The [Rights of Persons with Disabilities Act, 2016](#), defines a caregiver as any person, including parents and other family members, who, with or without payment, provides care, support or assistance to a person with a disability. The Act outlines the requirements for a caregiver allowance for those who care for people with high support needs.

The [Mental Health Act 2017](#) defines a caregiver as 'a person who resides with a person with mental illness and is responsible for providing care to that person and includes a relative or any other person who performs this function, either free or with remuneration'.

Family members are expected to act as primary caregivers to older adults. Multi-generational co-residence with children and grandchildren is widely prevalent in India.

The [National Policy on Senior Citizens, 2011](#), describes the need to strengthen the family system so family members can provide care and support for older persons at home. Institutional care is described as 'the last resort'.





CARER RECOGNITION (CONT.)



INDIA

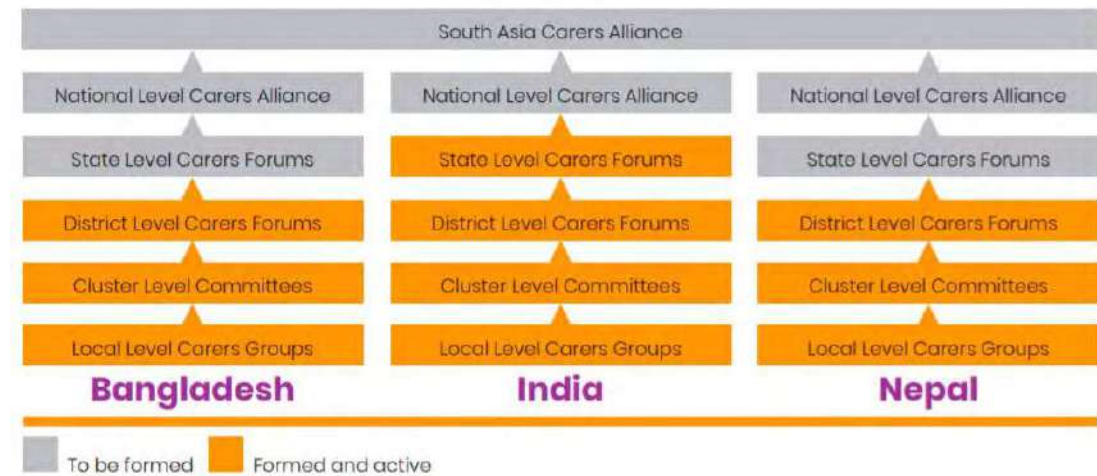
RECOGNITION

Carers Worldwide has helped to federate village-level caregiver groups into cluster-level groups and establish five district-level Carer Associations. Additionally, four State Level Carer Forums have been formed—in Karnataka, Andhra Pradesh, Jharkhand and Odisha. The associations meet quarterly to formulate responses to issues raised in the village groups, plan engagement with government officials and other stakeholders, and organise events at a district-level. [LEARN MORE](#)



Government officials are now recognising the individual and collective needs of caregivers. For example, the Commissioner of Disability for the Government of Karnataka announced in 2018 a 100% commitment to supporting caregivers and scaling-up the work across the state. A question about caregivers has been included in the Karnataka Disability census, but the census has been delayed due to a change in government and COVID-19.

The goal is to transition from a grassroots caregivers' initiative to a robust movement of civic society. By the end of 2019, 73,000 carers and family members had been reached.



OPPORTUNITIES



Continue to strengthen the collective voice of family caregivers at the district, state and national levels to recognise unpaid caregivers in policy initiatives.

Encourage family caregivers to be represented on the National Council for Senior Citizens as they were not included in the council composition.

Promote the inclusion of caregivers in policy and practice. Carers Worldwide is preparing State Level Action Plans in collaboration with the State Level Carer Forums, along with a range of toolkits for other organisations and government, to enable better and more enhanced inclusion of caregivers in policy and practice. In 2021–2022, Carers Worldwide will be forming an India National Alliance of Carers.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



INDIA

ALLOWANCE & TAX INCENTIVES

Caregivers do not receive any form of caregiver allowance in India.

The [National Policy on Senior Citizens](#), 2011, calls for tax incentives for those taking care of older family members.

Caregivers of persons with a physical or mental disability are eligible for an income tax exemption. As outlined in the [Income Tax Act](#), 1961, section 80 DD, the caregivers are eligible for a fixed deductible on income tax based on the dependent's degree of disability, which can be due to physical or mental health problems. A recent amendment of this law has increased this exemption amount.

The [Rights of Persons with Disabilities Act](#), 2016, has a provision for a caregiver allowance to persons with disabilities with high support needs, but that allowance has been offered in only a few isolated districts. It has not been formally implemented by any state.

[LEARN MORE](#)



PENSION

Take up of social security benefits in India is patchy and work-related pension is only available to approximately 10% of those in the formal workforce. Other pensions are available for the older adults, widowed individuals and those who are disabled. [LEARN MORE](#)

There is no pension exclusively for caregivers. However, the [Indira Gandhi National Old Age Pension Scheme](#) (IGNOAPS) provides for a non-contributory pension to people over 60 years of age who reside in a household that lives below the poverty line. Additional funds are available for eligible senior citizens who have concomitant responsibility for grandchildren and women.



OPPORTUNITIES



Provide direct financial support to family caregivers through the private and/or public sector.

Provide tax incentives to family caregivers of older family members so the caring contribution is practically and financially possible.

Expand the IGNOAPS policy so anyone over 60 years of age who lives in poverty and cares for anyone, not just grandchildren and women (e.g., a disabled son, husband, etc.), can receive an additional pension.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



INDIA

WORK & CARE

Indian employment law does not provide for caregivers' rights. [LEARN MORE](#)

A majority of the workforce in India belongs to the informal sector and therefore does not receive benefits such as paid leave or flexible working arrangements.

A survey by Carers Worldwide found that up to 97% of unpaid caregivers and their families in the rural areas of Karnataka, Jharkhand, Odisha and Andhra Pradesh live in poverty. Carers Worldwide helps unpaid caregivers establish livelihoods, largely through home-based businesses, that coexist with their caring responsibilities. Financial support is made possible with loans through carer groups, further empowering and supporting the participants.

Some family caregivers are accessing employment through local advocacy and application of the Mahatma Gandhi National Rural Employment Guarantee Act, 2005. Through a project funded by the Commonwealth Foundation, more caregivers know about this programme and are accessing the benefits. [LEARN MORE](#)

Since the onset of COVID-19, there is a growing awareness among urban employers (especially multinationals) of the important role of caregivers. Carers Worldwide is developing training and consultancy packages to advise companies in supporting employees who are family caregivers.



EDUCATION & CARE

[The Right of Children to Free and Compulsory Education Act](#), 2009, stipulates that every child aged 6 to 14 years shall have the right to free and compulsory education in a neighbourhood school until completion of elementary education. (This does not apply to the states of Jammu and Kashmir.) This Act effectively provides adult family caregivers of children with disabilities with daily respite; however, in reality, most children with disabilities cannot access or are not accepted into mainstream school. Furthermore, there are no specific provisions to ensure that young caregivers are expressly included in this legislation. Young caregivers are already known to quit school or attend irregularly due to caring commitments.

Carers Worldwide is striving to make changes by identifying young caregivers and working with them to return to school, building social connections at young caregiver groups and providing welfare assessments and support. Approximately 300 young caregivers have returned successfully to school since 2012.

OPPORTUNITIES



Introduce systemic change in the workforce allowing family caregivers to provide care for their family while continuing to participate in formal employment.

Engage with school authorities to raise awareness of young caregivers who may have dropped out or who attend school sporadically.

Make every effort to recognise and identify young caregivers as a disadvantaged group in order to ensure they cannot be discriminated against when trying to access education.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



INDIA

RESPIRE CARE

Respite care is in short supply, inaccessible or unaffordable to most in India. As a result, it is common for caregivers to report feeling socially isolated and stressed, with no free time. To overcome this issue, since 2012 Carers Worldwide has provided 2,825 caregivers with access to respite and short breaks from caring in order to help them relax and rejuvenate.

Centres such as the [Elders & Dementia Center](#), [Nema Elder Care](#), [Heritage](#), [Nightingale](#), [AajiCare](#) and [ElderAid](#) provide respite for those who can afford the fees. Services include:

- in-home respite care;
- elder home-based respite daycare;
- elder home-based respite care; and
- medical respite care for older adults.

[Community Caring Centres](#) is an initiative by Carers Worldwide and partner organisations to provide alternative daycare for children with disabilities, while at the same time providing a break for their caregivers. Family caregivers can use the time to engage in the workforce or to socialise with others. One such centre, in the state of Odisha, is managed by Carers Worldwide partner [Ekta](#) and is funded by the local government. A physiotherapist, special educator and language therapist provide support services for the children at the centre. Currently there are 22 Community Caring Centres operating in the regions supported by Carers Worldwide. The centres are very popular and there is constant demand for new centres to be opened.

EMOTIONAL & SOCIAL SUPPORT

The Mental Health Act calls for mental health services to support family caregivers of persons with mental illness. The Act establishes a Central Mental Health Authority (CMHA) and State Mental Health Authorities (SMHA), which must include two representatives who care for persons with mental illness or who are from organisations representing caregivers.

Carers Worldwide has led the establishment of self-help groups, allowing family caregivers to come together for emotional support. To date, 557 groups have been facilitated into self-sustaining operations.

Health camps for caregivers are organised through a partnership of Carers Worldwide and local organisations at a project level. The work involves mobilizing local government doctors to provide consultation and diagnosis free of charge to caregivers.

Carers Worldwide has launched the [Barefoot Counselling](#) initiative, which trains community members and caregivers to provide mental health first aid to carers. To date, have been 120 counsellors trained.



OPPORTUNITIES



Increase respite care funding and make respite services affordable and more readily available to all family caregivers.

In addition to old age homes, establish other alternative caring mechanisms such as community-based caring centres to provide day time care. This would allow senior citizens to remain living at home while also providing caregivers with free time in which they could pursue livelihood opportunities or have respite.

Ensure better recognition of caregivers' health needs by local government health authorities; increased mental health and counselling support for caregivers; and the establishment of telephone helplines for immediate support.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



INDIA

Information and training on specific conditions are provided by many state- and national-level NGOs in India. [LEARN MORE](#)

[ARDSI](#) (Alzheimer's and Related Disorders Society of India) is one of the main resources for dementia caregivers and people with dementia. ARDSI is involved in providing dementia and caregiving awareness activities, developing services, training family members and professionals, and undertaking research. ARDSI also runs helplines to provide information on Alzheimer's and caregiving.

[Adveka Foundation](#) is a non-profit, non-governmental organisation that focuses on the mental well-being of caregivers of people with physical and/or mental health issues. Sessions are designed to increase caregivers resilience, develop healthy coping skills and reduce their feelings of burden and stress.

[Caregiver Saathi](#)™ works to acknowledge and support caregivers of patients with terminal illness or chronic conditions, to improve their lives and well-being. Programmes help caregivers understand themselves, their role and challenges, equipping them with skills to manage and cope. Workshops, coaching, counselling and support groups are provided.

[Carers Worldwide](#) and its partners spread information on coping with caring and access to services through its network of carers groups. This is a key component of building capacity of caregivers in the cluster-level committees and carers associations.

[HelpAge India](#) works to help elders fight isolation, poverty and neglect. HelpAge supports many initiatives for elders including dementia care and palliative care.

[Hope Ek A.S.H.A](#) is a voluntary organisation dedicated to the care of Alzheimer's disease patients and their caregivers. Established in 2001, this organisation provides information, training, online support and services for patients and their caregivers.

OPPORTUNITIES



Seek funding to establish a telephone helpline at the state level in India. The goal is to have a resource in each of India's 29 states.

Supplement the Carers Worldwide 2019 policy review paper with information, advice and support (IAS) materials for carers, in combination with the telephone helpline.



 **Hope Ek A.S.H.A.**
Give Care...Who cannot care for themselves

INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN INDIA

The [Carers Worldwide model](#) is an innovative carer practice. It encompasses and incorporates IACO's principles—recognition, equal opportunities, information and knowledge, health and well-being, employment and financial security. Carers Worldwide integrates these principles to bring about systemic change by all sectors in the global South to facilitate the provision of support for individual carers and their families to bring them better health, well-being and economic security.

The model is comprised of five core elements that together transform the holistic well-being of carers:



The impact of the model is measured within and across countries of operation at the policy, delivery and individual carer levels. Adopted on a larger scale, the Carers Worldwide model has the potential to transform and/or support improvements in the lives of family carers in multiple countries. The application of the model is facilitating sustainable change in:

India – creating new opportunities for recognition and support for family caregivers in public policy

Nepal – promoting social and economic empowerment of carers by strengthening women-led carers associations

Bangladesh – achieving socioeconomic inclusion of vulnerable family carers



Carers Worldwide (established in 2012) works with family carers in low- and middle-income countries. It aims to improve support, services, and recognition for anyone living with the challenges of caring for a family member or friend who is ill, frail, or disabled, or who has mental health problems.

Currently, Carers Worldwide, based in the UK, is working with 10 partner organisations across India, Nepal and Bangladesh, transforming the lives of over 73,000 carers and family members to date. As a catalyst, Carers Worldwide is entering into alliances with other international NGOs in South Asia to increase its reach and continue promoting sustainable support services and long-lasting policy change.

Special thanks to Anil Patil, Founder and Executive Director, Carers Worldwide, who provided expertise, answered questions and participated in the review of this chapter.

SOURCES:

- Carers Worldwide. (2019). [Carers Worldwide policy review for carers in India. Carers in India Policy Review.](#)
- Gupta, R., Rowe, N., & Pillai, V.K. (2009). Perceived caregiver burden in India: Implications for social services. *Affilia*, 24(1), 69–79.
- Shaji, K.S. & Reddy, M.S. (2012). [Caregiving: a public health priority. Indian Journal of Psychological Medicine, 34\(4\), 303-305.](#)
- Math, S.B., Gowda, G.S., Basavaraju, V., et al. (2019). The Rights of Persons with Disability Act, 2016: Challenges and opportunities. *Indian Journal of Psychiatry*, 61(Suppl 4), S809-S815.
- Nooreyzedan, N., Abraham, A., Singh Chandel, A. & AZB & Partners. (2015). Employment and employee benefits in India: overview. [Thomson Reuters Practical Law.](#)
- Nicholson, V. (2019). Just because they care: developing the capacity of family carers to advocate for their rights. [Commonwealth Foundation.](#)
- Ugargol, A.P., Hutter, I., James, K.S. & Bailey, A. (2016). Care needs and caregivers: Associations and effects of living arrangements on caregiving to older adults in India. *Ageing International*, 41, 193-213.

In Ireland, the term ‘family carer’ is most frequently used. Family carers are people who provide regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability.



POPULATION DENSITY.....72 per sq km*
POPULATION URBAN63%*
MEDIAN AGE38.2 years*
TOTAL DEPENDENCY RATIO.....52.7**

* [Worldometer](#)

** [Central Statistics Office \(2016\)](#) Dependents are defined for statistical purposes as people outside the normal working age of 15–64. Dependency ratios are used to give a useful indication of the age structure of a population with young (0–14) and old (65+) shown as a percentage of the population of working age (15–64).



IRELAND

499,904¹ CARERS

10.1%² OF POPULATION

13% of Population 15 yrs and older.

¹ [Personal Communication Dec 2020 Care Alliance Ireland & Central Statistics Office](#)

² [Ireland 2020 Population: 4,956,456 \(Worldometer\)](#)



CARER RECOGNITION

The [National Carers Strategy' 2012](#) serves as the framework for supporting carers. The strategy defines a carer as 'someone who is providing an ongoing significant level of care to a person who is in need of care in the home due to illness or disability or frailty'. It recognises the contribution of young carers and identifies them as requiring focus.

The Four National Goals for carers are as follows:

1. Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person for whom they are caring.
2. Support carers to manage their physical, mental and emotional health and well-being.
3. Support carers to care with confidence through the provision of adequate information, training, services and supports.
4. Empower carers to participate as fully as possible in economic and social life.

[Young carers](#) are children and young people under the age of 18 whose lives are in some way affected because they provide care, assistance or support to another family member in the home. Young adult carers are recognised as a separate group and are aged between 18 and 24 years.

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



IRELAND

The [Department of Social Protection](#) hosts an Annual Carers' Forum as part of its commitments under the National Carers' Strategy. The objective of the Forum, attended by individual family carers, representatives of carer's organisations and officials from various Government Departments, is to provide carers with a voice at policy level. The Forum also provides an opportunity for other Government Departments to meet with carer's representative groups and individual family carers to gain a deeper insight into the issues they are most concerned about and learn of and assess priorities within the sector. Issues such as State supports for carers, carer health and well-being, training, housing supports, transport issues and supports for young carers are discussed at this annual event. This level of engagement has helped inform some considerable improvements that have been introduced for carers in recent years.



An Roinn Coimisce Sóisialaí
Department of Social Protection

As part of the [Programme for Government \(2020\)](#), the current government has committed to updating the National Carers' Strategy.





CARER RECOGNITION (CONT.)



IRELAND

RECOGNITION PROGRAMS

Since 2007, [Care Alliance Ireland](#) has acted as lead organisation in the coordination of the annual **National Carers Week**, held annually in June. Care Alliance Ireland collaborates with not-for-profit partner organisations and many others in organising the week. Events take place across all counties in Ireland, celebrating Ireland's 391,000 family carers. [LEARN MORE ABOUT NATIONAL CARERS WEEK 2020](#)

carers week



Once a year, carers are acknowledged through the [Netwatch Carer of the Year Awards](#). Two categories are awarded:



Carer of the Year:
Family Carers Ireland selects one winner from every county. Each county winner then goes forward for the overall Netwatch Carer of the Year.

Young Carer of the Year:
Family Carers Ireland selects one winner from every region (i.e., Leinster, Munster, Connacht, Ulster) and each wins the Netwatch Young Carer of the Year.

OPPORTUNITIES



Visibility of carers has come to the fore with COVID-19. More people are beginning to have a fuller appreciation for the challenges carers face—including the isolation and the need to protect their care recipient, irrespective of COVID-19.



As outlined in [Family Caring and Minority Populations Discussion Paper #9](#), the increasing diversity in Ireland serves as an impetus to understand the needs of minority groups within family care, and provide culturally appropriate services and supports.

Ireland's population is ageing, and data shows that older people make a significant contribution to society through their caregiving role; 31% of individuals over the age of 70 provide help and care for their spouses, relatives (not including grandchildren), neighbours or friends. Older family carers often remain invisible, and the particular needs of, and challenges facing, older family carers need to be highlighted and supports provided. [LEARN MORE](#)



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



IRELAND

BENEFITS AND ALLOWANCE

[Carer's Benefit](#) is a payment made to insured people who leave the workforce to provide full-time care. It can be claimed for a total period of 104 weeks for each person being cared for. It may be claimed as a single continuous period or in any number of periods. The claimant must be over 16 years of age.

[Carer's Allowance](#) is a means-tested weekly payment for full-time care. Carers must be at least 18 years of age and not employed, self-employed or taking education outside the home for more than 18.5 hours a week.

The [Domiciliary Care Allowance](#) is a monthly payment for a child under 16 years of age with a severe disability, who requires ongoing care and attention, substantially over and above the care and attention usually required by a child of the same age. It is not means tested.

[Carer's Support Grant](#) is an automatic annual payment made to recipients of either Carer's Allowance or Carer's Benefit for use as they see fit. Carers assessed as ineligible for the Carer's Allowance due to exceeding the means test can apply for this grant. To qualify for the Carer's Support Grant, an individual must meet the following criteria:



- aged 16 or over;
- ordinarily resident in the State;
- living with the care recipient or, if not, contactable quickly by a direct system of communication (e.g. telephone or alarm);
- caring for the person on a full-time basis; and
- caring for the person for at least six months.

[Carers GP Visit Card](#) allows carers in receipt of the Carer's Allowance or Carer's Benefit to visit their GP free of charge.

PENSIONS

Pension [Credits for Carers](#) are awarded if a person gives up work to care for someone and gets the Carer's Allowance or Carer's Benefit. People on Carer's Leave who do not get either of these payments are also entitled to these credits.

A small number of long-term carers, mostly women, may not accrue either any or sufficient social insurance contributions over their working age, thus making them ineligible for a future state contributory pension.

The [HomeCaring Periods Scheme](#) (operating since 2012) makes it easier for people who take time out of their working life to care for children or adults to qualify for a [State Pension \(Contributory\)](#). Anyone born on or after September 1, 1946, and who has cared full-time for an adult or child, can apply for the HomeCaring Periods Scheme. This programme can only be used when the State (Contributory) Pension is calculated using the Total Contributions Approach.

OPPORTUNITIES



As recommended in Family Carers Ireland's [Submission to the Department of Justice and Equality on Flexible Working](#), it would be helpful if the government streamlined the transition between the Carer's Benefit and Carer's Allowance.

There are financial implications for carers, particularly women, of interrupting employment for caregiving. It affects not only their earnings during their working life, but also impacts their income in later life. The financial impact of caring on pensions must be at the heart of pension policy debates.

A pending publication of research on the cost of disability and caring will help inform future changes to income support measures.



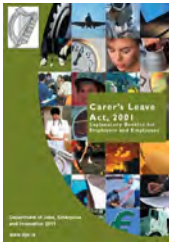
WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



IRELAND

WORK & CARE



[Carer's Leave Act 2001](#) provides employees with the right to temporary unpaid leave to provide full-time care for someone in demonstrable need. The care recipient does not need to be a family member. To be eligible, the person must have been in the continuous employment of the employer from whom the leave is taken for at least 12 months

before the leave. An hours worked threshold is not specified. The leave must be for a minimum of 13 weeks (the employer has the right to refuse a request for less than 13 weeks) and a maximum of 104 weeks, during which time their employment rights are protected. The leave may be taken in one continuous period or for a number of separate periods with at least six weeks between leave periods.

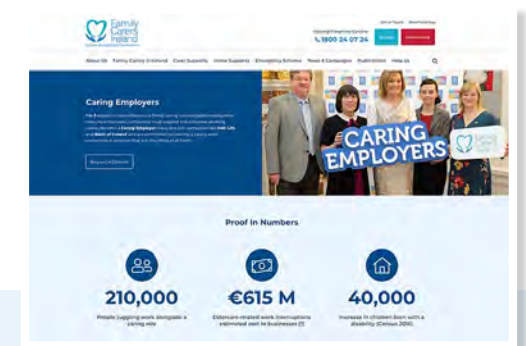
[European Directive on Work Life Balance for Parents and Carers](#) (2019) addresses the increased participation of women in the workforce and the use of family-related leaves and flexible working arrangements.

[Force Majeure Leave](#) allows for a short leave for urgent family reasons when the immediate presence of the employee is indispensable owing to injury or illness of a close family member. The maximum amount of leave is three days in any 12-month period or five days in a 36-month period.

EDUCATION & CARE



The [National Youth Strategy 2015-2020](#) released by the [Department of Children and Youth Affairs](#), commits to raising awareness and understanding among education, health and youth service providers of the signs that young people have caring responsibilities, and the impact caring has on them in relation to their education, health and recreation pursuits.



OPPORTUNITIES



New initiatives are being developed that focus on engagement with employers, for example [Caring Employers](#). Caring Employers partners with companies in a pledge to ensure carers feel supported and empowered in the workplace.

There are opportunity costs for family carers who give up work to provide care, but there are also important consequences for the wider economy. For example, the lower participation of women of working age can have a detrimental effect on pensions. This is an issue that should be of major concern to the state. Better supports that enable family carers to combine work and caring could help alleviate this concern.

Recommendations from Family Carers Ireland's [Submission to the Department of Justice and Equality on Flexible Working](#) include better promotion of the right to leaves; greater flexibility regarding time-off provisions; changes to qualifications for the leave, including the ability to have a leave for care of less than 13 weeks; and increased oversight to ensure compliance.

Projects that integrate youth services and formal education can play a greater role in mitigating the negative impacts of caring. Increasing work with the tertiary education sector is also required regarding students' caring responsibilities and enhanced support needs.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



IRELAND

RESPIRE CARE

Respite services are provided to individuals following an assessment of health needs of the individual user and are subject to the resources available. Information about respite services is available through local primary care teams/public health nurses or local health offices. While recognised as important, the system capacity to provide this service is limited—83% of carers' loved ones have no access to suitable respite. [LEARN MORE ABOUT THE IMPACT OF CARING](#)

The [Health Service Executive \(HSE\)](#) provides health services directly and funds voluntary organisations to provide supports and services to individuals and their carers.

An [Emergency Care Plan](#) is available for family carers to record the support and care needs of each of their care recipients. The completed summary is sent to Family Carers Ireland, which issues the carer with a wallet card and manages a 24-hour emergency helpline.



EMOTIONAL & SOCIAL

A [Carer's Needs Assessment](#) has been developed in collaboration with organisations in the caring sector. There is, however, little evidence of this assessment tool being prioritised within the health and social care system. If adopted, mainstreamed and broadened to include all full-time carers, the assessment will have the potential to dramatically alter family carer experiences within the system.

Online supports, such as [Family Carer Online Support Group Ireland's Facebook](#) page, have the potential to reach large numbers of family carers, particularly those who are geographically isolated and/or unable or reluctant to access face-to-face supports.

A public consultation on improving home care services highlights the heavy reliance on family carers to provide the bulk of care, including to those with highly complex care needs, and in turn highlights the importance of supporting family carers by providing home care on a continuum. Related issues are the lack of a statutory entitlement to home care, variations in service provision and unregulated home care services. [LEARN MORE](#)

OPPORTUNITIES



Increased regulation and pressure on acute services has made the delivery of more respite care challenging and ultimately unsuccessful. More resources for home-based respite care services would be welcome. It is necessary to explore novel and adaptive respite options, such as hotel breaks, in-home respite and others. There is also potential to develop more innovative models of day care in Ireland that are informed by developments in other European countries.

Family carers need greater support than that which is currently provided through home care services. There is strong support for a radical shift away from the current narrow, supply-side approach to home care toward a more person-centred, demand-led, integrated model of provision that reflects the specific needs of recipients and supports family carers.

The Department of Health is developing a new statutory scheme and system of regulation for home support services that provides an opportunity for making this radical shift. [LEARN MORE](#)



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.

A number of organisations provide training for family carers. [Family Carers Ireland](#), established in 2016 through the merger of the Carers Association and Caring for Carers, provides a range of one-day, non-accredited training for topic-specific workshops, subject to available funding.

A confidential, friendly and supportive [National Freephone Careline](#) offered by Family Carers Ireland provides experienced and trained staff and volunteers who listen to the concerns of callers and offer practical information, advice and referrals on a range of topics including:

- Carer's Allowance;
- Carer's Benefit;
- Carer's Support Grant;
- Family Carers Ireland services, including counselling, respite and training;
- carer support groups;
- membership of Family Carers Ireland; and
- supports available from local authorities, Ireland Health Services and Department of Social Protection.

[Carer support managers](#) assist carers, including young carers, with specific queries relating to their caring role, advocate on their behalf and carry out individual carer well-being reviews to help identify supports they may need. Family Carers Ireland's network of carer support managers are available to meet one-on-one with family carers at their support centres around the country.

Social Protection Minister Heather Humphreys has [announced](#) the provision of €5 million through the Dormant Accounts Action Plan 2020 to upskill and fund education and training opportunities for carers, including young carers and people with disabilities.

[The Alzheimer Society of Ireland](#) provides online and face-to-face dementia-specific training and information for carers. Topics to support family carers include:

- information on how a diagnosis is made, memory clinics and next steps if a diagnosis is made;
- tips on how family carers can look after themselves;
- information about signs, symptoms and progression and behaviour changes;
- information and tips to help with day-to-day life, such as communication and safety in the home;
- carer stories; and
- links to supports and services.



IRELAND

OPPORTUNITIES



Greater use of specific one-off online training and education interventions, such as [Facebook](#), will result in reaching more family carers.



Consideration should be given to using psycho-educational interventions in some circumstances that focus on the dyad (family carer and care recipient), their relationship, the impact of caring on their relationship, and facilitating conversations about caring issues and future care planning.

INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN IRELAND

Online Outreach: In March 2020, Care Alliance Ireland established an **online family carer support project** through the private [Facebook group](#) platform, effectively reaching and engaging with over 1,900 family carers across Ireland.

The project has seven discrete activities:

- | | |
|-----------------------------|----------------------------|
| 1) Posting/moderating. | 5) Distribution of booklet |
| 2) 1-2-1 casework through | resources. |
| private messages. | 6) Informal competitions. |
| 3) Educative interventions; | 7) Online book club. |
| 4) Online quizzes. | |

Facebook has unquestionable reach, in particular among women aged 45–54, where the highest concentration of caring is reported.

Quantitative analysis of retention indicates that 95% of participants have remained in the group since it was established.

The Carer's Assembly is an innovative approach developed by the [Centre for Economic and Social Research on Dementia](#) to engage with family carers on issues affecting them and consider which issues are the most important for immediate policy attention by government.

Twenty-eight carers took part in the Assembly meeting in October 2019. They listened to four presentations, discussed the evidence highlighted in the presentations and then ranked the priorities as follows:

1. Homecare services.
2. Economic support.
3. Respite care.
4. Social support.

The recommendations were brought to the 2019 policy dialogue on home care. A short [clip](#) of the Carer Assembly and Carer Assembly [proceedings](#) are available.



Care Alliance Ireland (established in 1995) is a national network of 95 voluntary organisations supporting family carers by providing information, developing research and policy, sharing resources, and instigating opportunities for collaboration.

Special thanks to the following individuals who provided expertise, answered questions and participated in the review of this chapter:

- Liam O'Sullivan, Executive Director, Care Alliance Ireland
- Zoe Hughes, Policy & Research Officer, Care Alliance Ireland
- Dr Maria Pierce, Independent Researcher, Dublin.

SOURCES:

- The Alzheimer Society of Ireland. [Services in My County](#).
- Eurocarers. Towards carer-friendly societies. [Eurocarers country profiles \(2020\)](#).
- Family Carers Ireland. [Website](#).
- Family Carers Ireland, the College of Psychiatrists of Ireland and the UCD School of Nursing, Midwifery & Health Systems. (2019). [The Physical, Mental and Psychological Impact of Caring. Health Service Executive \(2020\)](#).
- McGarrigle, C., Ward, M., Scarlett, S., & Kenny, R. A. (2020). [The Contributions of the Over 70s to Irish Society: Results from Wave 5 of the Irish Longitudinal Study on Ageing](#).
- [The Irish Longitudinal Study](#) on Ageing Trinity College Dublin Dublin 2.
- Mulligan, E., Wijeratne, D., & Maher, M. (2019) Pensions in Ireland: The Perspectives of Irish Citizens and Implications for Pensions Systems and Reforms in Ireland and other EU Member States. Institute for Lifecourse and Society, NUI Galway. ISBN: 78-1-908358-61-5.
- The Institute of Public Health in Ireland. (2018). [Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation](#). Dublin: Institute of Public Health in Ireland.

In Israel, the term 'family caregiver' is used. Family caregivers are individuals, such as family members, friends or other significant people, who take on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness.

POPULATION DENSITY..... 401.9 per sq km*
POPULATION URBAN 91.5%*
MEDIAN AGE 30 years*
TOTAL DEPENDENCY RATIO..... 66.9**

* The Central Bureau of Statistics (CBS), Population Statistical Abstract of Israel 2020

** Ibid. Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64) in 2020.



ISRAEL

1,213,523¹ CARERS
21%² OF POPULATION
aged 20 plus

¹ Central Bureau of Statistics 2019 Social Survey

² Ibid.



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



LEGISLATION

There is no word in Hebrew for family caregiver. A new word, 'ben mishpacha metapel', has been introduced.

The civil [Israeli Family Law \(Maintenance\) Amendment Law of 1959](#) mandates that citizens must support their parents and the parents of their spouses—provided they can adequately satisfy their own needs and those of their spouses and their minor children. Parents have the right to sue their adult children for maintenance.



In 2013, Israel adopted a [National Strategic Plan to Address Alzheimer's and Other Types of Dementia](#), which places emphasis on family caregivers, identifying them as a specific segment of society needing attention and support.

RECOGNITION

The government has recognised the family as a target population for the development of supportive services. The [Ministry of Labor, Social Affairs and Services](#) (MOLSA) is leading policy development for the family as a target population with specific needs. A goal is to establish a professional doctrine and organisational models to provide assistance and support to family caregivers to be disseminated and adopted by social services. [LEARN MORE](#)

Two important activities have laid the groundwork for awareness and policy development for family caregivers:

1. The [Central Bureau of Statistics](#) (CBS) conducted a survey in 2019 that included questions about family caregivers. This was an important step because the last time that family caregivers were included in a CBS survey was in 2006.
2. A [cross-sectoral team](#) was established in March 2020 in response to the COVID-19 pandemic. The team works on behalf of the Prime Minister's Office to promote recognition and support services for family members. This is the first time such a broad collaboration of government ministries has been established to discuss the issue of family caregivers.

Seven ministries are participating, along with representation from social sector organisations, [ESHEJDC](#), [Caregivers Israel](#) and the [Myers-JDC-Brookdale Institute](#) as expert resources.

The team is focussing on two key issues:

1. Facilitate/simplify the family caregiver role by making relevant information accessible and record the caregiver in health and long-term care records so that they become recognised as an important source of information and support.
2. Make existing support and assistance accessible to family caregivers to strengthen their resilience in dealing with the important and complex task they perform.

During the COVID-19 lockdown of 2020–2021, the team published [special guidelines](#) for family caregivers.





CARER RECOGNITION (CONT.)



ISRAEL



OPPORTUNITIES

Promote national policies to support Israeli caregivers with an expectation that they will be automatically informed of relevant information to support them in their caring role, while maintaining privacy and confidentiality.

Identify the primary caregiver in the care recipient's health and long-term care records so that they become recognised as an important source of information and support.

Adopt the recommendations for caregivers in the World Health Organisation's 2020 Policy Brief, [Preventing and managing COVID-19 across long-term care services](#).

These include:

- recording the main caregiver in health and long-term care records;
- providing information, training, support and, if possible, respite care at a national level to caregivers, particularly those caring for older people living with dementia, including information on how to manage increased caregiving responsibilities and stress. Consider establishing a telephone helpline or online portal to offer advice, information and support;
- conducting an assessment to monitor family caregiver needs;
- exploring new ways of providing support services to caregivers through technology and support caregivers in accessing relevant technologies; and
- introducing and/or expanding financial and psychosocial support for family caregivers.





FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



ISRAEL

BENEFITS

The [Long-Term Care Benefit](#) is provided to people who have reached [retirement age](#), who live in their own home and are in need of assistance from another person in performing daily activities. The benefit is designed to help older adults and the family members who are taking care of them. The benefit is paid based on [six levels of entitlement](#). Recipients can choose to receive both a benefit in cash and long-term care services, which include: personal care at home, visit in a daycare centre, supply of absorbent products, and supply of a panic button and laundry services. [LEARN MORE ABOUT ELIGIBILITY AND ACCESS](#)



As of November 1, 2018, long-term care benefit recipients are able to receive all or part of the benefit in cash instead of nursing services. Benefit rates and selection options vary according to the level of benefit. A full cash benefit can be provided if the recipient employs a full-time caregiver for at least 12 hours per day, six days per week, and the caregiver is not a family member. [LEARN](#)

[MORE](#)

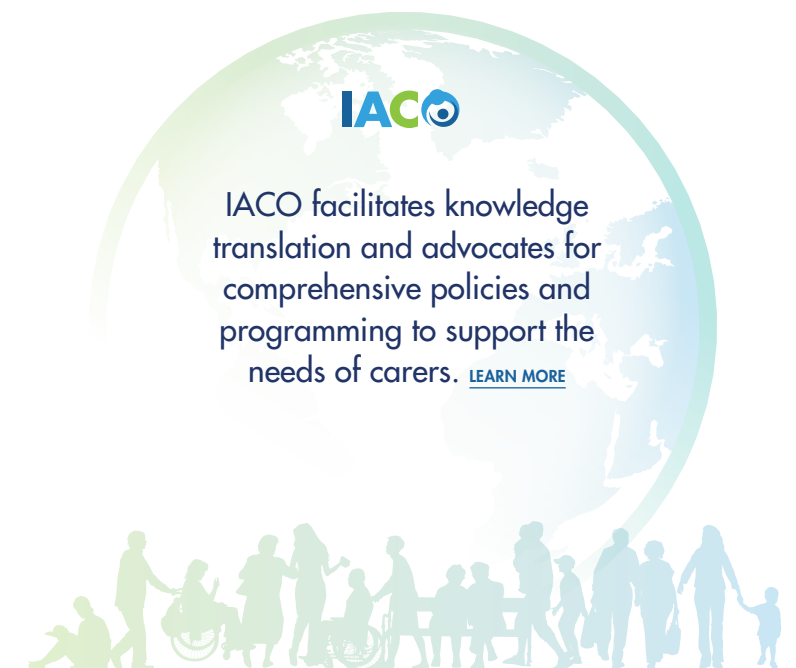
The [Family Caregiver Benefit](#), established in April 2018, permits family caregivers to be paid to care for their relative in need. The degree of family closeness does not matter as long as the local committee determines the caregiver is suitable and the care recipient approves.

If the family member's application to be a caregiver is approved, then they are considered an employee for all intents and purposes and their salary must not be lower than the minimum wage. The scope of working hours depends on the level of nursing benefit to which the patient is entitled.

[Disabled Child Benefit and Related Benefits](#) are monthly allowances for children with a disability. The amount paid is based on the degree of disability and the child's dependence on others. Eligibility for the benefit may also include entitlement to other rights and benefits, such as obtaining a permit to employ a foreign worker to care for the child, as well as various discounts.

[Disability Pension and Related Benefits](#) are monthly benefits paid to those whose physical, intellectual or psychological impairments affect their ability to earn a living (or the ability of a homemaker to function in the household) by at least 50%. Eligibility for the Disability Pension also grants benefits in other areas, such as housing, transportation and health.

The [Special Services Benefit \(Attendance Allowance\)](#) is paid to adults for whom a medical disability of at least 75% has been established (with regard to special services). It also provided to [General Disability Pension](#) recipients for whom a medical disability of at least 60% has been established, and who require significant assistance from another person in performing daily activities, or who need constant supervision to prevent them from posing a risk to their own lives or the lives of others.





FINANCIAL SUPPORT (CONT.)



ISRAEL

TAX CREDITS

The [Tax Credit for a Parent or Spouse Living in an Institution](#) is available if the spouse or parent of an employee resides in a special institution. The credit is equal to 35% of the difference between the amount paid for the spouse/parent to live in the institution and the obligatory 12.5% of income paid by the applicant. The credit is conditional on the amount of income of the individual in the institution and the combined income of the individual and their spouse not exceeding a defined threshold.

The [Tax Credit for a Child in Housing Outside the Home](#) is paid to the parent or legal spouse for their child living with a disability to live in housing outside the home. The credit is equal to 35% of the difference between the amount paid for the child to live in the housing framework outside the home (provided the expenses exceed 1/8 of their taxable income) and the obligatory 12.5% of income paid by the parent.

[Tax Credit Points for a Child or Adult with Disabilities](#) is a programme where the Israel Tax Authority grants two tax credit points to parents of a child or a person over the age of 18 who is defined as 'disabled'. In the absence of parents, the benefit may be given to a sibling of the person with a disability who has been appointed their [guardian](#) of 'body and property'.

OPPORTUNITIES



Preserve pension rights for those who leave the workplace to care for a sick person.

Provide professional training for those who have left the workplace and want to return to the labour market.

Enable the transfer of a tax credit to an assigned family member when a self-employed person becomes ill and as a result has no income.

Provide funding to support caregivers for older people that is at least equitable to the support provided for childcare.

Develop policy, procedures, training and infrastructure to support paid family caregivers.

IACO believe that to ensure sustainable long-term care systems, the unique needs and contributions of carers must be considered in health and social policies and programming. [LEARN MORE](#)





WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



WORK & CARE

The law prohibits the discrimination against an employee because they are the relative of a person with a disability. [LEARN MORE](#)

Employed caregivers are allowed to be absent to provide family care. The number of days is tied to the nature of the condition and family member—child, spouse or parent. [LEARN MORE](#)

- Six days are permitted for a parent, if they are completely dependent on others to perform daily activities and up to 60 days per year if the spouse has a malignant disease.
- Six of accrued sick days per year can be taken due to illness of a parent or spouse's parent. Partial days (hours) that the employee misses because of a parent's illness can also be taken.
- Up to eight days per year can be taken for an illness of a child under 16 years (16 days for a single parent).
- 90 days per year can be taken for the care of a child under 18 years who has a malignant illness or requires dialysis (110 days for a single parent).
- Up to 18 days per year can be taken for child with special needs (36 days for single parents).
- Up to seven days can be taken for the care of a spouse or parent who has donated an organ.

If the employer consents, an employee can use their unearned sick days for the balance of the year, use accrued vacation days or request to take [unpaid leave](#) to care for a family member.

An employee is entitled to severance pay by the Severance Compensation Act 1963 if they are quitting the job to care for an ill spouse. Caregivers are only eligible if changes to work conditions cannot be made to enable the employee to continue working while providing care.

OPPORTUNITIES



Preserve pension rights to ensure that work leave benefits are consistent between employees and self-employed workers.

Extend the existing work leave rights of 60 sick days for spouses of cancer patients to individuals caring for spouses with other advanced-stage diseases that are life-threatening or require long-term care, such as dementia and muscular dystrophy.

Promote conditions and rights for employed caregivers whose family member is in a home hospice and who need more days off work and more emotional support.

Collect information about young carers in order to develop policies and resources to support them at home and at school.





HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



ISRAEL

RESPITE CARE

Vacation (nofshon) is a framework that provides care and supervision to older adults for a short period of time, permitting family caregivers a break from their caring responsibilities. It is provided through the [Ministry of Welfare](#).

It is possible, under certain conditions, to receive vacations for [older adults](#) for rehabilitation and in [nursing homes](#). The holiday stay is for a short period and includes accommodation, meals, personal care, health services, social services and social activities. Vacations are designated for nursing older adults and ultra-Orthodox older adults.

Families of children with disabilities are entitled to a vacation for the child once a year for two weeks.



IACO is working to increase global awareness and recognition of carers around the world and with opinion leaders and key global health and social organisations.

[LEARN MORE](#)

OPPORTUNITIES



Ensure caregivers are acknowledged and supported physically and emotionally by health care professionals.

Provide more support for family caregivers of people with dementia.

Enable access to leisure and activity hours as respite.

Provide referrals to social activities, sports, etc.





HEALTH & WELL-BEING (CONT.)



ISRAEL

EMOTIONAL & SOCIAL SUPPORT

Day centres for older adults are daily frameworks for older adults living in their home, whose function and ability to manage the household has decreased and who need help with personal care. The day centre allows older adults and their families to receive supportive services and prevent or delay their removal from home to an institutional setting. There are 166 centres that are open 5 to 6 days a week from morning to noon, and are operated through local associations for older adults, under the supervision of the service for older adults in the Ministry of Welfare.

If the family member needs a full-time caregiver, it may be possible to receive permission to employ a foreign nursing care worker. [LEARN MORE](#)

NGOs and the Ministry of Social Affairs and Services (MSAS) have developed programs to assess the needs of family members and provide referrals to suitable services and help in navigating the service system using the approach of managed care. These models are based on the combined professional workforce of social workers and volunteers.

Masa (Journey) is a programme led by the Ministry of Labour and Social Affairs of Israel, [National Insurance Institute](#) and Eshel JDC. It appoints special social workers for family caregivers in the community to enhance integration of services to care for family members. The programme is offered in the social services bureaus in thirty local authorities.

[Caregivers Israel Association](#) provides personal phone consultation to family members who are caregivers in order to offer personal guidance and support, information and direction to community services, coping strategies and follow-up.

[LEARN MORE ABOUT THE IMPORTANCE OF COUNSELLING AND SUPPORT.](#)



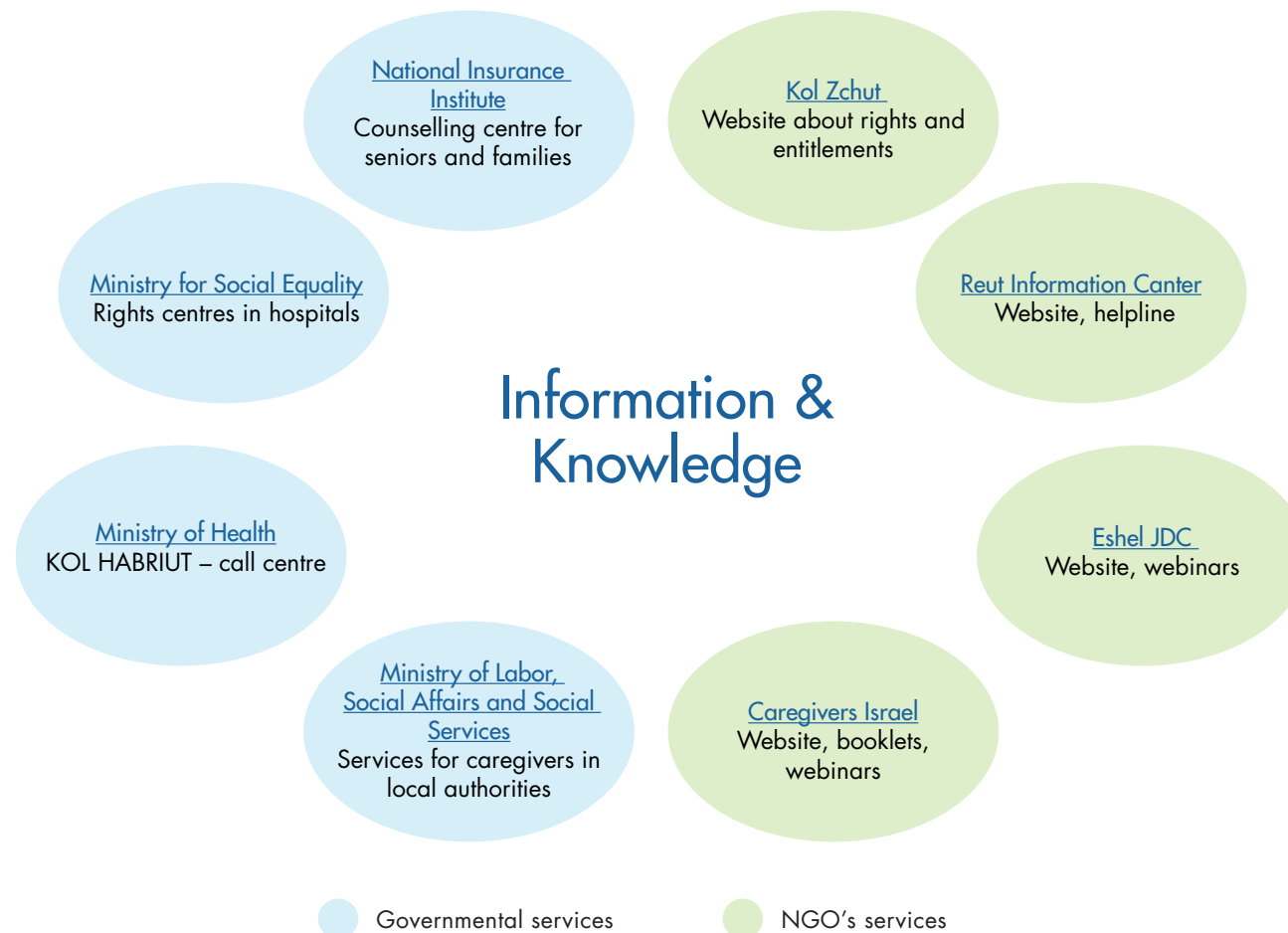


INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



Non-profit organisations provide information through websites, seminars, lectures and learning groups and hotlines for family members who are caregivers.



OPPORTUNITIES

Provide a government website to centralize the relevant information from all government bodies for caregivers—their rights, how to access services and the processes for implementation.

Offer support groups for caregivers regardless of the disease or condition of the person for whom they are providing care.



INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN ISRAEL

Caregiver-friendly workplace for public sector employees who are caring for family members has been developed by [JDC Israel Eshel](#) and [Caregivers Israel](#), in collaboration with the [Civil Service Commission](#). In September 2019, the Civil Service Commissioner introduced a horizontal policy directive applicable to family caregivers. As a consequence, ministry management are responsible for designing and implementing an organisational environment that promotes a culture of support for and recognition of family caregivers. The work environment must allow caregivers to be protected from repercussions in the workplace related to their family caregiving responsibilities.

In each ministry, an assistance committee is responsible for family caregiver employees, which is headed by the Director of Human Resources or someone on their behalf.

The powers of the committee are:

- 1 Confirmation of use of employee sick days for caregiving
- 2 Authorize employees caring for a family member to go on unpaid leave for up to 24 days a year
- 3 Grant permission to leave the unit, work part-time, work from another branch or other solutions
- 4 Assistance hours – approval of up to 3 hours of assistance per month for employees caring for their family member, without deduction from their salary
- 5 Either approve a part-time job for a period of caregiving, or approve a job from another branch, or approve another possible solution, depending on the circumstances
- 6 Arrange for professional counselling for family caregiver employees

Caregivers Israel and Eshel-JDC are running a programme of Caregiver Friendly Workplaces in several private sector organizations. CareGivers Israel helps organisations develop and implement internal human resources policies that encourage talent retention, recognise family caregivers and support them.

[Learn more](#)



Caregivers Israel (established in 2014) is a non-profit organization that is committed to raising public awareness to the caregiving issue; to recognising and supporting Israel's family caregivers, as being fundamental to strong families that create stable communities.

Special thanks to the following individuals at Caregivers Israel who provided expertise, answered questions and participated in the review of this chapter:

- Rachel Ledany, Chief Executive Officer
- Professor Eli Carmeli, Board Chair

SOURCES:

- Mevorach, G. (October 2016). [Israel national report for the third review and appraisal cycle of the implementation of the Madrid International Plan of Action on Ageing and its Regional Implementation Strategy](#) (MIPAA/RIS). State of Israel. Ministry of Labour and Social Affairs Service for Senior Citizen. Jerusalem. P. 4.
- Bentur, N. & Sternberg, S.A. (2019). [Dementia care in Israel: top down and bottom up processes](#). Israel Journal of Health Policy Research, 22.
- Hacker, D. (2019). [Aging Population And The Law: A Comparative Approach Filial Piety In Israel: Between The Law In The Books And The Law In Action](#). Frontiers of Law In China, 14 (2). Doi 10.3868/S050-008-019-0009-6
- [International Alliance of Carer Organizations](#)
- S.Azran-Shadmon, S. Resnizky, M. Laron, J. Brodsky, (2018). [Review of Programs for Family Caregivers of People with Dementia](#). Jerusalem: Myers-JDC-Brookdale Institute

In Italy, the term 'family caregiver' is most often used.



POPULATION DENSITY..... 206 per sq km*
POPULATION URBAN 69.5%*
MEDIAN AGE 46.7 years**
TOTAL DEPENDENCY RATIO..... 57***

* [Worldometer](#)

** [Eurostat 2019](#)

*** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64) in 2020.
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



ITALY

7,500,000¹ CARERS
14.9%² OF POPULATION

¹ [Istituto Nazionale di Statistika](#)

² Italy 2020 Population: 60,439,461 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



ITALY

LEGISLATION

The [Provisions for the recognition and support of family caregivers Act](#) was finalised in July 2020 and, as of November 2020, is being examined by the Italian Senate's Commission on Employment and Social Protection. This draft legislation defines caregivers (caregiver familiari), as well as support measures that should be made available to the informal caregiver via a 'support network' made up of social workers, nurses, general practitioners and voluntary organisations. It also specifies that the designation of caregiver cannot be granted to more than one person per care recipient.

In 2017, a national Caregiver Fund of €20 million was established via the [budget law for 2018](#), which was then to be increased by €5 million for each successive year until 2021. The Fund was created to cover the expenditure of the legislative measures aimed at recognising the social and economic value of the unpaid family caregiver.

Family caregivers are defined as 'individuals who provide continuous care, on a voluntary basis and for free, to a spouse, partner, family member or relative up to the second degree (third degree in some exceptional cases) who, due to illness, infirmity or disability, is not self-sufficient, able to take care of him/herself and requires comprehensive and continuous longterm care' (Provisions for the recognition and support of family caregivers Act)

RECOGNITION



Italy has a strong tradition of family care, and women in Italy provide the majority (77%) of informal care for older generations within the family. [LEARN MORE](#)

Caregivers are formally recognised in various Italian regions. There are 20 regions in Italy, five of which have a broader level of autonomy, although all are autonomous with defined powers. Emilia Romagna Region was the first, with [Regional Law 28 March 2014](#) (Legge Regionale), to recognise the role of the family caregiver and the need to implement support interventions. Unpaid caregivers are also formally recognised in Lombardy, Lazio, Abruzzo, Puglia and Campania.

[Disegno di Legge n. 2266](#), the national framework law for the recognition and enhancement of the family caregiver, 2016, established the 'National day of the family caregiver, to be celebrated every year on the last Saturday of the month of May'. It is expected that the social value of the care and family assistance will be discussed in schools (article 7).

Many regions and associations hold events recognising family caregivers between May 19 and June 6. The events of 2020 marked the tenth 'Caregiver Day' in Emilia Romagna. The programme included six free webinars addressing caregiving.

Since 2011, [Anziani e Non Solo](#) (ANS) has promoted [Family Caregiver Days](#) with seminars, conferences and cultural and educational events designed to enhance the profile of family caregivers.



Many associations in Italy, as members of the Eurocarers, including ANS, acknowledged October 6, 2020, as the first [European Day of Family Caregiver](#).





CARER RECOGNITION (CONT.)



ITALY

YOUNG CARERS

According to recent national statistics, more than 390,000 young and young adult persons (15–24 years) have with caregiving responsibilities in Italy, corresponding to 6.6% of the population in that age group [IStat]. There is little awareness of and attention given by decision-makers and professional persons who come in contact with young carers.



There are no practices or any policies for young caregivers under 18 years of age. [Presentation on Young Carers in Italy](#)

IACO members work together and independently to raise awareness of carers and their issues. [LEARN MORE](#)

OPPORTUNITIES



Expand the definition of unpaid caregiver, improve full policy implementation of the 2018 Budget Law and decrease regional fragmentation.

Conduct more research into the extent of young caregivers in Italy and develop policies that acknowledge and support them.





FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



ITALY

ALLOWANCE

The primary support for disabled older people at home is the 'Companion' or 'Attendance' Allowance ([Indennità di Accompagnamento](#)), which is paid monthly. This allowance is a nationwide universal measure, accessible to all citizens, including children who are certified as totally dependent. Paid by the [National Institute of Social Security](#) (INPS), it can be spent in any way chosen by the recipient, including to employ low-cost migrant help at home.

The allowance is not means tested and is paid to the carer who may also be eligible to purchase a car without having to pay VAT. This allowance makes up most of the 0.86% of Italy's GDP spent on cash allowances. The allowance aims to support the family of a person with severe limitations and encourage family members to take care of the dependent person, thereby avoiding recourse to residential care and helping to reduce public LTC expenditure. ([Sentence n° 1268, 21st January 2005](#))

The [Family Assistance Voucher](#), Buono assistenza familiare (BAF), is an economic contribution, disbursed by the Lombardy Region, aimed at families who use a caregiver for the care of a non-self-sufficient elderly person. It cannot exceed 50% of the family assistant's social security expenses and has a maximum limit per recipient. The recipient of the bonus is also entitled to an additional contribution fee in situations where there is further fragility within the family unit, which can be measured using the parameters and scores referred to in the Deliberation of the Regional Government 915/2018 concerning the Family Factor, Fattore Famiglia (FFL). For example, consideration is given to the number of children; the presence of a mortgage on the main residence; and the presence in the family unit of elderly people, pregnant women or other people with disabilities or non-self-sufficient people in addition to the assisted person.

Similar programmes are available in other regions (e.g., Emilia Romagna), but typically the measure is limited because the income ceiling for eligibility is very low. [LEARN MORE](#)

PENSION CREDITS

Qualified caregivers are entitled to national social security contributions paid by the State within a total limit of three years, upon declaration of the hours of assistance issued to INPS on a quarterly basis.

[Disegno di Legge n. 2128](#), (Rules for the recognition and support of the family caregiver, 2015), states that pension contributions are paid during the care leave (contributi figurativi). The amount is equivalent to those who do domestic work and is paid by the State for the period of assistance and care work actually carried out starting from the moment of recognition of serious handicap of the assisted family member. These contributions are added to those already paid for work activities in order to allow access to early retirement upon accrual of 30 years of total contributions.

Caregivers also have access to a form of early retirement originally designed for heavy workers ('lavoratori gravosi'). The 'quota 41 pension' requires 41 years of contributions and is typically reserved for workers who have accrued at least 12 months of contributions before the age of 19. [LEARN MORE](#)

OPPORTUNITIES



Provide financial support to all unpaid carers, not just unpaid carers of disabled or ill persons.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



ITALY

WORK & CARE

Care leave is granted only to workers who have to care for severely disabled relatives.

Law No 183/2010 (Article 24) introduced the principle of 'sole carer', which means that in a household, only one worker can attend the needs of a severely disabled person. Available to public and private employees only (self-employed and those employed in domestic and household services are excluded), the law states that the caregiver is entitled to two different types of care leave:

1. Three working days of paid leave per month for short-term leave:

Parents and close relatives of the person with the disability can access this leave, even when not living together with the person in need. The three working days can be taken in half days or on a piecemeal hourly basis to tend to a relative in case of an emergency or to accompany them to medical appointments.

2. Up to two years paid leave (Congedo biennale retribuito

(Legge n. 151/2001)) to care for a seriously disabled child or relative: The leave is paid at 100% of earnings up to an annual ceiling adapted over time according to inflation. Parents, close relatives and individuals with severe disabilities can access this leave as long as the caregiver is co-resident with the person with a disability. This criteria limits access to the paid leave. The reason is that the regulation was initially designed for working parents with seriously disabled children. Only recently did it apply to informal caregivers of frail older people.

As an EU member state, Italy is expected to implement the rights introduced by the 2019 European Directive on Work-Life Balance for Parents and Carers by 2022. This includes the new carers' leave of five days per year and the promotion of flexible working arrangements for carers. While already fully complying with the Directive, the Italian legislation narrowly defines the role of family caregiver.



The Provisions for the Recognition and Support of Family Caregivers Act recognises the right of the caregiver to reschedule working hours and to be given priority in choosing the place of work closest to the care recipient's home. It outlines modifications to labour legislation to accomplish this. It also provides for specific programs to support the placement or relocation of family caregivers at the end of their care and assistance activities.

DA.L.I.A is funded by the Italian Ministry for Equal Opportunities, and has been operating since 2004. It includes projects and interventions to support family and professional caregivers with training, information, support for social and professional inclusion, and ways to combat discrimination. The project aims to research and disseminate good practices for reconciliation of work and care for employed caregivers, and to increase the visibility of the obstacles facing working caregivers as well as their challenges regarding work-life balance. DA.L.I.A works with the National Confederation of Craftsmanship and Small and Medium Enterprises (Confederazione Nazionale dell'Artigianato e della Piccola e Media Impresa - CNA) to raise awareness of the problems experienced by working caregivers. It also forms and supports work groups to co-design mediating company policies and actively promotes and supports companies that are committed to supporting their caregiver workers.



WORK & EDUCATION (CONT.)

Founded in 1946, [Confederazione Nazionale dell'Artigianato e della Piccola e Media Impresa \(CNA\)](#) represents the largest association in the territory. In fact, the enormous spread of skilled work and small businesses, both in large cities and in small municipalities, corresponds to its widespread presence. CNA is present in all Italian provinces with 18 regional CNAs and 96 territorial CNAs, with about 7,500 collaborators, active in over 1,100 regional, territorial and local offices.

EDUCATION & CARE

The [Care2work project](#) is a free digital learning course specifically designed for young carers. This short, fun, engaging and empowering digital tool helps young carers explore the skills and competencies they have acquired through their experiences in providing care to a family member. There are also modules for professionals working with young carers.



[Educating to care](#) is a project funded by the Rotary Club of Castelvetro and carried out in partnership with the CFP Nazareno di Carpi. The project offers support to children who play a significant role in the care of a sick, disabled family member. By working with the schools, caregiving experts can:

- inform teachers who, if properly trained, can play a fundamental role in the early identification and support for collaboration between care and school activities; and
- reach students who, when made aware, can provide adequate support to fellow caregivers, assist and welcome them, and help them overcome the stigma and stereotypes associated with illness and disability.

The project will carry out a preliminary awareness-raising and training course aimed at a group of teachers, tutors and educators who work within the Institute. This awareness-raising process is aimed at two class groups, to examine the meaning and impact of caregiving. The project will be integrated with the 'Personal Path' activities.



ITALY

OPPORTUNITIES



Expand and improve the scope and definition of the variety of leaves available to carers in Italy in order to capture the needs of all informal caregivers in a more comprehensive and inclusive manner.

Extend the policies introduced to support families during COVID-19, such as paid leave up to a maximum of 12 days (instead of three days under normal circumstances) a month, granted to workers with care and family duties of persons with disabilities and elderly/non autonomous members of the family, into a regular programme.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



ITALY

RESPITE CARE

There is no national respite care available, but some regions have introduced measures to give unpaid carers rest periods or breaks (holidays or temporary respite).

The Municipality of Bologna has allocated €1 million to support caregivers. The [Caregiver 2020](#) project introduces a system of support and help for families that provide informal caregiving to a person with a disability or dependency. It includes a telephone counselling service activated in spring 2020 that provides caregivers with access to professional advice and guidance. The project is also expected to include counselling at home to help families with the management of practical tasks.

The Modena Court of Justice offers an [information service](#), managed by volunteers, that targets people who provide care to a person with a dependency or disability and who are their legal guardian as a result of their functional limitations.

EMOTIONAL & SOCIAL SUPPORT

Family caregiver groups organised by ANS online and/or in person provide opportunities for sharing daily experiences.

ANS manages peer-support groups for family caregivers on behalf of the Terre D'Argine District that includes the provision of information, guidance, training and self-help resources. The self-help groups focus on family caregivers of adults with a dependency as well as parents of children and adolescents with a disability. The group meetings are supported by a facilitator to help caregivers generate social networks to overcome loneliness, reduce stress, develop individual skills in dealing with problems, and foster solidarity and mutual help.

ANS also started the Young Caregiver group for youth up to 24 years of age who take care of a family member or loved one in need of help.

[TOGETHER](#) supports the social inclusion and engagement of young carers in Germany, Italy, Greece and the UK by helping them and care professionals to adopt a 'whole family approach'. All members of the household (including the care recipient) are encouraged to communicate openly about the illness and caregiving. The goal of TOGETHER is to prevent/reduce the negative impacts of caregiving on young caregivers, as well as to improve their well-being, social inclusion and community engagement.





INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



ITALY

A variety of associations provide information and resources to caregivers. This varies by region and is provided by patient or carer organisations.

A [central online information hub](#) created by ANS bridges the information gap and meets the needs of caregivers across Italy. The website provides information about ongoing policy developments, what it means to be a caregiver, and ways of maintaining and improving their well-being and ability to balance caregiving, social and professional responsibilities.

The information hub also provides access to an [online training course](#) on the caregiver role and caregiving challenges, available services and measures to improve care coordination, as well as daily caregiving tips (e.g., nutrition, hygiene, help with movement and mobilization, age-related pathologies, dementia, communication between the carer and care recipient, first aid). The course can be accessed online or via DVD and the materials can be used in individual self-training or for group courses.



ANS has created also online courses for caregivers: 'Assisting people with ALS: basic training elements' and 'Course to assist patients with dementia and Alzheimer's disease'. The courses have been active since 2011 and operate on the MOODLE platform. To date 2,353 accounts have been activated and funded by local societies, health care companies and voluntary associations.

The online training allows caregivers to work at their own pace. The courses are comprised of three basic modules for a total of 18 teaching units. Each unit includes self-assessment tests.

In-depth modules also cover care recipient pathologies with links to sites, materials and videos selected from the network. Self-training can be integrated with the creation of self-help groups and with classroom/laboratory activities in which experts connect the general elements learned in self-training with the specific situations of care and assistance.

ANS promotes e-learning and class-based training courses for caregivers in the Carpi and Correggio Districts.

1 The Role and Problems of Caregiving

- Family caregiver: a complex role and job
- Care commitment: risk of stress and burnout
- Communication and relationships in care
- The legal protection of the elderly
- Illness and grief
- Life after care (postcaregiving)

2 Know the Services and Organises Care Work

- The system of local services
- Caregivers and family assistants
- The caregiver as an employer
- Organise the care activity
- Home security

3 Assistance for the Functions of Everyday Life

- Food hygiene
- Power
- Personal hygiene
- Help with movement and mobilization
- The pathologies of the elderly
- Alzheimer's disease: activity and care relationship
- Health emergency: first aid

INNOVATIVE CARER PRACTICES

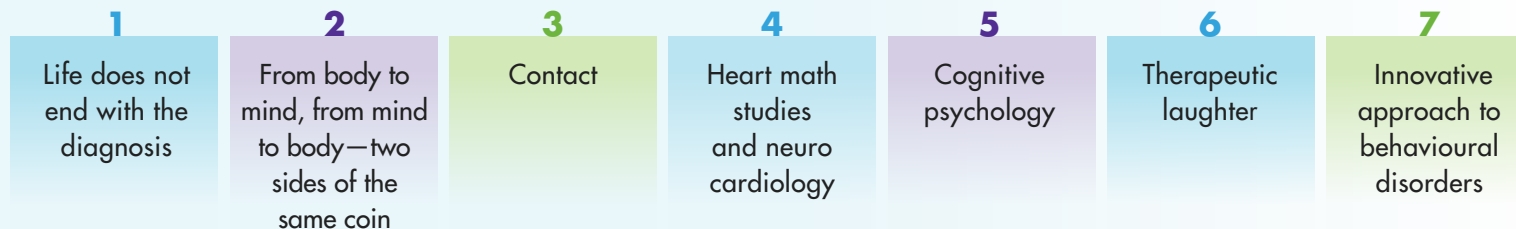


Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN ITALY

The [Sente-Mente® Model](#) seeks to help caregivers see and nurture the vital core of their loved ones suffering from dementia. This begins with new ways of thinking to preserve the person's dignity and avoid defining people by their disease. The Model helps caregivers move from helplessness toward self-effectiveness and improve their own well-being while maintaining a meaningful and empathic relationship with their loved ones.

The Sente-Mente® Model builds on seven pillars:



The innovative aspects of this model include:

Empowering caregivers to overcome the pathology-driven model of care by focussing on every individual's ability to experience emotions.

Adopting an effective and person-centred care model.

Shedding light on the inner beauty that continues to exist in the person suffering from dementia.

Teaching caregivers to get in contact with themselves and with their care recipient with kindness and tact is the first step to restoring wellness and health in both caregivers and care recipients.



Anziani e Non Solo (ANS) is a social cooperative that has been operating since 2004 in the social innovation sector. It focusses on the design and implementation of interventions, products and services in the field of welfare assistance and social inclusion.

Special thank you to Stecy Yghemonos, Executive Director, [Eurocarers](#), for his expertise and review of this chapter.

SOURCES:

- Anziani e Non Solo. [Family Caregivers](#).
- European Parliament, Directorate-General for Internal Policies. (2014). [The social and employment situation in Italy](#).
- ISTAT. (2015). [Rapporto sulle condizioni di salute e ricorso ai servizi sanitari in Italia e nell'Unione Europea](#).
- Boccaletti, L. (2017). Presentation – [Young carers in Italy – an overview](#).

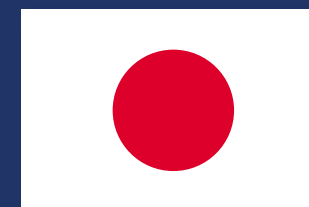
In Japan, the term 'kazoku kaigoshu' (family caregiver) is most frequently used.

POPULATION DENSITY..... 347 per sq km*
POPULATION URBAN 91.8%*
MEDIAN AGE 48.4 years*
TOTAL DEPENDENCY RATIO..... 69**

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64).
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



JAPAN

6,280,000¹ CAREGIVERS
5%² OF POPULATION

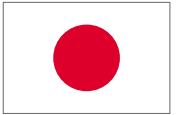
¹ 2017 Employment Status Survey, subjects of survey are aged 15+

² Japan 2020 Population: 126,397,022 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



JAPAN

LEGISLATION

There is no legislation specific to family caregivers, rights or livelihood.

In March 2020, the [Saitama Carer Support Ordinance](#) (Saimata-ken Kears Shien Jourei) was enacted in Saitama Prefecture (one of 47 prefectures in Japan) to provide support for caregivers as a system, the first in Japan. The Saitama Prefectural Assembly 2020 ordinance contains specific provisions to support minors who are family caregivers. [LEARN MORE](#)

The Act on the Prevention of Elder Abuse, Support for Caregivers of Elderly Persons and Other Related Matters 2005 references family caregivers only to prevent abuse, and is insufficient as a policy to support caregivers.

YOUNG CARERS

The Saitama Prefectural Statement of Young carer is part of the 2020 Saitama Carer Support Ordinance. 'Young carers' are defined as 17 and younger—a group considered 'children' under Japan's Child Welfare Act. The ordinance states that the prefectural government 'must support them' to ensure appropriate educational opportunities and sound growth, both physically and mentally, as well as to help them foster their independence. The Health, Labor and Welfare Ministry plans to conduct a nationwide survey (National Young Carers Survey) of high schools and other such educational institutions in December 2020 to assess the current situation of children who are responsible for taking care of their families on a daily basis.

RECOGNITION

The Upper House Budget Committee and Committee on Health, Labour and Welfare discussed family caregivers in 2018–2019.

The Framework for Promoting Dementia Care, formulated in June 2019, identifies support for health and care services and for caregivers as one of its five pillars. [LEARN MORE](#)

[Carers Japan Vision](#) draws on the learnings from other countries to reinforce messages and has, for example, translated the Carers' Charter from Denmark.

There is no national kazoku kaigoshia (family caregiver) appreciation day.

OPPORTUNITIES



Carers Japan continues to actively advocate for the establishment of a national Carer Support Promotion Act.

Carers Japan is drawing attention to the issue of social isolation among family caregivers and lobbying for this to be included in the recently enhanced general consultation (one-stop service) provided for in the Social Welfare Act, amended in 2020.

The Association is also promoting legislation to support family caregivers at prefectural and municipal levels, similar to what has been enacted in the Saitama Prefecture, to provide support for carers as a system.

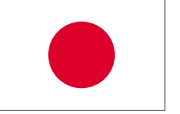


37,100 people aged 15–19 in Japan were working or going to school while providing home care to a sick or incapacitated family member as of 2017. Recently released [research](#) shows that one in 20 high school students in the east Japan prefecture of Saitama takes care of family members. [LEARN MORE](#)



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



JAPAN

There is no tax benefit specific to family caregivers. Within the Long Term Care Insurance (LTCI) system costs of certain services delivered qualify as tax deductions medical expenses. These deductions can be claimed by the care recipient only. [LEARN MORE](#)

Family Care Leave Benefit:

Employees **receive** 67% of their salary (increased from 40% in 2016) during family care leave if they are covered by employment insurance, take the leave to provide care for their family who need care, and meet certain criteria. [LEARN MORE](#)



Women represent 80% of those who have quit their jobs due to caregiving.

Caregivers also have difficulty going back to work and face economic disadvantages throughout their lives. [\(Statistics Bureau of Japan, 2017 Employment Status Survey\)](#)

According to the International Alliance of Carer Organizations, unpaid caregiving has become one of the most important social and economic policy issues worldwide. As the population ages, unpaid carers will continue to play a critical role providing substantial global economic value.

OPPORTUNITIES



In addition to financial security, Carers Japan believes that exemption from social insurance premium payments during a family care leave is essential as a minimum protection of carers' rights.





WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



JAPAN

WORK & CARE

Japan's [Plan for Dynamic Engagement of All Citizens](#), approved by Cabinet in 2016, asserts 'no one forced to leave their jobs for providing nursing care (meaning family caregiving)' as one of its priorities. [LEARN MORE](#)

Leave provisions to fulfill caregiving responsibilities are for up to 93 days per family member, either continuously or in up to three installments. [LEARN MORE](#)

Family caregivers can also apply up to two times in a three-year period for shorter workdays and can apply for an exemption from overtime work until family care ends. [LEARN MORE](#)

Family caregivers can take five days per year of '[Time Off for Caregivers](#)' to handle long-term care.

Employers may not deny a leave request.

In addition, in conjunction with the Equal Opportunity Act, companies must establish measures to prevent superiors or colleagues from creating working environments that are hostile to taking childcare or caregiver leave. Companies must also establish measures to support employees caring for their children and families.

Examples of the measures to achieve this goal include:

A new [online portal](#) for 'no one forced to leave their jobs for nursing home care' (Ministry of Health Labour and Welfare).

A subsidy for work-life balance (a course to support prevention of worker turnover due to caregiving roles) to support companies' efforts to help employees balance work and family care (2016).



Assistance in the development of care support plans.

A variety of systems are available based on the [Child and Family Care Leave Act](#) to help caregivers balance work and family care. This includes family care leave benefits, measures to shorten prescribed working hours, exemption/limitation on overtime work or late-night work, and measures to prevent harassment related to family care leave.

EDUCATION & CARE



The Saitama Carer Support Ordinance requires schools and boards of education in the prefecture to support young carers to gain an education. Under the [Ordinance](#), the

prefectural government is required to draw up a promotional plan to support young carers. Possible support measures to be incorporated include having homeroom teachers and other officials interview or visit homes of young carers, information sharing within school guidance counsellor associations and cooperation with school counsellors and social workers. [LEARN MORE](#)



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



JAPAN

RESPIRE CARE

A caregiver assessment is not conducted, and respite care is not available as a program specific to carers themselves.

Services under the national long-term care insurance system for care recipients function as respite for family caregivers—short-stay in residential care, day care and in-home care. Availability of these services varies widely from one municipality to another.



EMOTIONAL & SOCIAL

Community General Support Centers, which are established in accordance with the Long-Term Care Insurance Act, provide programmes to support family caregivers as a discretionary component of the Community Support Project.

In 2018, the Ministry of Health, Labour and Welfare (MHLW) produced the [Family Carer Support Manual](#) for Municipalities and Community General Support Centers: Supporting the Lives of Carers to enhance the function of community general support centers.

Consultation and support services are provided for families caring for people with dementia.



Carer support organisations run carer cafés in some progressive communities.



OPPORTUNITIES



Some municipalities provide counselling and consultation for caregivers. Carers Japan promotes the expansion of these measures across the country.



The 2018–2022 IACO strategic plan outlines four strategic priorities:

- Increase awareness and recognition of carers.
- Enhance understanding of the impact of caring.
- Create a global strategy and commitment to action for carers.
- Facilitate capacity building.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



JAPAN

The Ministry of Health Labour and Welfare (MHLW) and municipalities provide information through their websites and brochures. However, it is available separately within each field (e.g., older adults, disability, etc.), and caregivers often find it difficult to obtain the information they need.

Some municipalities independently organise classes for family caregivers, however they are not sufficient.

Carers Japan has published the Carer Handbook and 'Carer Support Guide for Your Town' to provide carers with basic information.



OPPORTUNITIES



The current system that provides information for carers is inadequate. Carers Japan would like to work with national, prefectural and local governments, as well as companies and others, to build a system that provides information in a flexible manner, addressing not only elder care but also the needs of various family caregivers, including young carers.

IACO is building a strong and vital network of carer organisations to establish a global understanding and recognition of the essential role of carers with respect to care recipients, health and social care systems, and society.



INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN JAPAN

In response to the COVID-19 pandemic, Carers Japan has developed and published [Carer Emergency Sheet \(Carers' Baton\)](#) to help caregivers transfer their roles to others in case of emergencies, including when they need to be isolated due to infection and other reasons.

[Carer Emergency Sheet
\(Carers' Baton\)](#)

Carers Japan asked the national government to address issues related to COVID-19 and carer support. In response, the government added a section for family caregivers to the COVID-19 Q&A page on the [Ministry of Health Labour and Welfare's website](#), including a list of [Community General Support Centres](#) for the country.

Since such a tool is essential in non-emergency situations as well for the smooth transition of a caregiving role, Carers Japan continues to refine the information so that it can be used more widely.



Carers Japan (established in 2010) aims to raise public awareness of family carer issues and solve problems faced by carers. The Association envisions a society in which care recipients and their carers can live without struggle. To that end Carers Japan undertakes advocacy, research, policy recommendations, enlightenment and provision of information and advice to carers.

Carers Japan also has Young Carers Project to promote support for young carers.

Special thanks to Mai Yamaguchi, Director, Carers Japan, who provided expertise, answered questions and participated in the review of this chapter

SOURCES:

- Baker & McKenzie. (2016). [Amendments to the Child and Family Care Leave Act and the Equal Opportunity Act](#).
- Ikeda, S. (2017). Family Care Leave and Job Quitting Due to Caregiving: Focus on the Need for Long-Term Leave. *Japan Labour Review*, 14(1), 25-44..

In New Zealand, the term 'carers' is most frequently used. Carers are people who care for friends, family, whānau (extended family) and aiga (family) members with a disability, health condition or illness who need help with everyday living.

POPULATION DENSITY..... 18 per sq km*
POPULATION URBAN 86.9%*
MEDIAN AGE 38 years*
TOTAL DEPENDENCY RATIO..... 55.8**

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64).
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



NEW ZEALAND

430,000+¹ CARERS

10%² OF POPULATION

¹ [NZ Census 2018](#)

² New Zealand 2020 Population: 4,829,948 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



NEW ZEALAND

LEGISLATION

There is no specific legislation in New Zealand that recognises or enhances the recognition of carers.

The [Government's vision for carers](#) was laid out in the 2008 Carers' Strategy:

'New Zealand is a society that values individuals, families, whānau and aiga¹ who support others who need help with their everyday living'.

To realize that vision, carers must have choices and opportunities to participate in family life, social activities, employment and education; and, carers' voices must be heard in decision-making that affects them.

The [New Zealand Carers' Strategy Action Plan 2014–2018](#) and most recently, the new [Mahi Aroha: Carers' Strategy Action Plan 2019–2023](#) identifies priority objectives including:

- carer health and well-being;
- accessing information and assistance to balance work, life and caring responsibilities; and
- increasing awareness and recognition of the carer role.

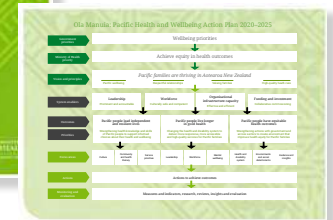
Young carers are a priority population in the government's strategy, and the 2019–2023 Action Plan specifies the inclusion of young carers in research, policy development and specific measures to help them to access support.

A range of other government strategies interconnect to promote recognition of carers. Strategies relevant to family caregiving include the [NZ Disability Strategy and Action Plan](#), [Better Later Life–He Oranga Kaumatua 2019–2034](#), and [Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025](#).

The [New Zealand Public Health and Disability Act 2000](#) has relevance for carers in relation to payment policy.



Carers' Strategy Action Plan
2019–2023



IACO facilitates knowledge translation and advocates for comprehensive policies and programming to support the needs of carers. [LEARN MORE](#)



¹ Term in the Samoan language meaning family.



CARER RECOGNITION (CONT.)



NEW ZEALAND

RECOGNITION

[Carers New Zealand](#) (Carers NZ) and the [Carers Alliance](#) are planning the country's first Carers Week in 2021 with nationwide events.

[She Cares](#), a web-based campaign hosted by Carers NZ, encourages recognition and awareness of women in caring roles. The campaign features real stories of some of NZ's incredible women carers and helpful suggestions on how to take 'mini-breaks' showcased on Carers NZ's website and Facebook page.



[CareWise](#) is both a programme and an awareness campaign to encourage carer friendliness at work by providing user-friendly tips, tools and recommendations to support employers.



Past campaigns have included a Year of Wellbeing for carers, reminding them with monthly themes to plan ways to self-care.

YOUNG CARERS



Young carers make up 8% of 15–24-year-old New Zealanders (2018 Census).

Carers NZ is the legal umbrella of Young Carers NZ (YCNZ), a network for children and young people up to the age of 24 who have caring responsibilities. Led by former young carers and an advisory panel of YCs, this network connects mainly via social media through a [Young Carers NZ Facebook page](#).

Carers NZ has developed print and web resources for parents and those working with young carers, and for young carers themselves. An advisory group helps guide the work of the network, which includes events, information, online get-togethers and media exposure to raise awareness of young caring. [LEARN MORE](#)

YCNZ has adapted [Saul Becker's](#) Multidimensional Assessment of Caring Activities (MACA) survey tool to build a profile of New Zealand's young carers.

OPPORTUNITIES



Carers NZ and the Carers Alliance have encouraged the government to review global carer legislation to inform future directions in New Zealand.

Making carers more visible is a strategic and political objective. Carers NZ recognises the need to pivot to having carers seen as a large and unique population in its own right across society, government, health and social services. There needs to be a 'head' of carers in key agencies, and perhaps a Minister for Carers. This pivot will require considerable new effort by the carer movement and may take years of effort to achieve. The experience of other nations will be helpful.

Information about NZ's young carer population is anticipated by 2022, providing an opportunity to compare and benchmark with other countries—particularly those that use the MACA tool.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



NEW ZEALAND

In 2013, New Zealand became one of the first countries in the world to introduce payment recognising the work of carers. This occurred following many years of human rights and court action led by families seeking to overturn discrimination for payment on the basis of family status.

[Resident Family Care](#) is for those caring for someone with high or very high support needs. Carers NZ and the Carers Alliance lobbied successive governments to improve the policy so eligibility was fairer; recent changes allow spouses and young carers aged 16–18 to receive payment. Pay rates are now on par with those of the formal support workforce (previously carers were paid the minimum wage). The payment is not asset or means tested. [LEARN MORE](#)

In addition to payment for carers, those providing significant levels of support, who cannot easily undertake paid employment due to caring, can receive the [Supported Living Payment](#) (SLP)—a benefit that is means and asset tested, and therefore not available to many carers. Spouses cannot receive the SLP. [LEARN MORE](#)

[Carer Support Subsidy](#) is allocated to thousands of New Zealand carers who are caring for people with disabilities, older people, those with long-term chronic conditions, and people with mental health problems. It is the only source of state support many carers receive. Structured currently as a modest daily payment to help carers access respite services (at home, or facility- or service-based), it is disliked by many carers due to the rigid rules governing its use.



OPPORTUNITIES



New Zealand does not currently offer a carer's allowance or non-means tested funds. There are discussions relating to a Universal Basic Income that would give all citizens, including carers, financial support regardless of the reason why they need this support, including being a carer.

A further area of study is recognition that it is not fair to over-rely on women to provide free care. Two-thirds of NZ's carers are women. In New Zealand, carers cannot get the Supported Living Payment if they are caring for a spouse—this barrier to financial support is an important women's issue.

IACO creates international partnerships and global advocacy that strengthens and honors the voice of caregivers.

[LEARN MORE](#)





WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



NEW ZEALAND

WORK & CARE

Almost 90% of New Zealand's carers are workforce age (15 to 65), but a COVID-19 survey by Carers NZ found that only 39% are able to participate in part- or full-time paid work.

Developed by Carers NZ and funded by the Ministry of Social Development, [CareWise](#) is a programme to help employers build carer-friendly workplaces. The programme was launched in May 2020 and is offered to employers at no cost. With public-facing communication as well as private access for employers, CareWise offers information and knowledge relating to work/care balance for both employers and working carers. Downloadable tools for employers are available once they have committed to being a carer-friendly workplace. CareWise employers are asked to welcome carers to apply for vacancies at all levels of their organisation.

The New Zealand Carers Strategy Action Plan 2019–2023 commits to supporting flexible study, training and education opportunities for young carers. The Plan also commits to working on ways to credit skills and experience toward any training, qualifications and/or employment.

[Employment Relations Act Part 6AA Flexible Working](#) gives New Zealanders (including carers) the right to request flexible working arrangements. COVID-19 has accelerated acceptance of flexible working across industries and is likely to yield new employment opportunities for those who need to work flexibly and/or from home due to caring.

EDUCATION & CARE

Carers NZ has partnered with the [Student Volunteer Army](#) to recognise the support young carers provide to friends and family members. The [SVA schools volunteering programme](#) allows students to record the hours they spend helping a friend or family member, to receive recognition for their important role. Young caring is a unique support category in the SVA programme, with most New Zealand secondary schools now participating.

Information and partnerships are being developed to support young carers early in their working lives, as an outcome of the [CareWise](#) programme. Carers NZ is also working with schools and tertiary institutes so they understand the impacts of youth caring on study and can take practical steps to support young carers as they plan to enter the workforce.



OPPORTUNITIES



Work/Life is now Carers NZ's top priority to help carers to:

- remain employed
- understand their options
- identify available assistance
- determine the options available for young carers



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



NEW ZEALAND

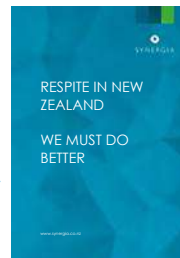
RESPITE CARE

Respite is one of the primary priorities for the coalition of NGOs in the Carers Alliance. It was addressed in the 2019 report to government, *Respite in New Zealand: We must do better.* [LEARN MORE](#)

The respite supports or services that are allocated by [Needs Assessment and Service Coordination \(NASC\)](#) organisations and funded by the Ministry include:

- [Carer Support](#);
- [individualised funding](#);
- family whānau home support (a 'buddy' or support worker for a few hours per week); and,
- a stay at a respite house or other facility.

There are a range of respite options available in each region. A list of services and contact information is available through the Ministry of Health. [LEARN MORE](#)



[Carer Support](#) is a subsidy to reimburse the costs of hiring help for respite care. It is available to full-time carers, defined as providing more than four hours per day of unpaid care to a disabled person. The amount of funding depends on the needs of the carer and the care receiver. Funding is through District Health Boards for people with age-related support needs, mental health and long-term medical conditions, and through the Ministry of Health for people with disabilities.

[I Choose](#), a more flexible form of Carer Support that was meant to be introduced by the Ministry, is on hold while a sustainable implementation plan is developed. The key changes enable greater flexibility in respite options, direct deposit of funds and fewer forms to complete.

It is necessary to ensure carers are well informed and receive fair treatment and funding in evolving flexible funding models (including respite), and the devolution of New Zealand's Carer Support Subsidy to personal budgets, giving them flexibility to purchase goods and services that give them a meaningful break.



Lose and Tita, from Terry Winn's national Caring Moments collection.

IACO will foster a worldwide movement to recognise and support carers through the creation and promotion of a Global Carers Strategy and Action Plan. [LEARN MORE](#)





HEALTH & WELL-BEING (CONT.)



NEW ZEALAND

EMOTIONAL & SOCIAL SUPPORT

Most Carers NZ resources and engagement with carers happen online or via the 0800 helpline. Supports include:

Helpline: Provides telephone support during business hours to answer individual inquiries, referring carers as needed to other sources of help and providing guidance as needed.

Email hotline: A growing number of Carers NZ's inquiries come via the internet 24/7. These range from requests for information to complex cases needing intensive advocacy with health and social service agencies.

Well-being resources: Offers information and resources about a range of topics important to carers. These include the [Time Out Guide](#) and [MeetUps Toolkit](#), both available for free download at the Carers NZ website.



Other resources include a [Take 1 Minute Take 5](#) feature that allows carers to choose from a menu of well-being audio and meditation exercises and fun uplifting videos. In addition, a strength-building 15-minute exercise programme for carers using stretchy bands ([Strength for Life](#)) and an audio and video follow-along well-being series ([Stretch Focus & Relax](#)) are available. Carers can also download planners to help them organise timeout and respite breaks.

[Supporting people to move at home](#) is a free print and web guide addressing injury prevention for staff and carers. It was developed by the Home and Community Health Association and Carers NZ, funded by Accident Compensation Corporation.



OPPORTUNITIES



There is growing emphasis in New Zealand on 'individualised funding' that allows for greater choice about how allocated resources are used to support carers and their care recipients. The [Flexible Funding To Support Disabled People and Their Families](#) report provides useful information on the scope and estimated costs of current flexible funding approaches.

Carers NZ intends to double the size of its 15K Facebook audience in 2021 as an influencing avenue for carers who cannot easily attend 'real world' events or participate in physical activism.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



NEW ZEALAND

INFORMATION

Information packs are provided to individual carers joining Carers NZ and in bulk amounts to Carers Alliance organisations and other community networks. Packs are available digitally and in print variations. Partners are able to tailor the information packs with their own resources before distributing them to carers in their networks.

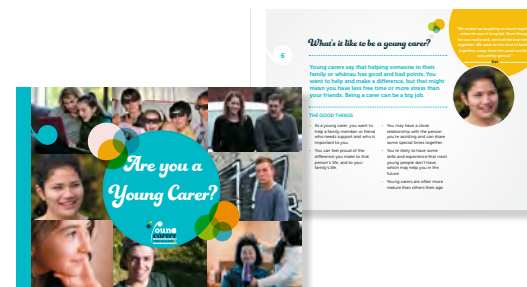
Advocacy for carers ensures they are given timely and sufficient help where possible. This is done with health, social service and government agencies, and with [Needs Assessment and Coordination Services](#) (the gateway to all publicly funded services for carers in New Zealand).

Social media offers a lively community of carers at www.facebook.com/carersnz and www.facebook.com/youngcarersnz.

e-news and alerts include regular e-newsletters that are distributed to an audience of about 12,000 and shared by other networks to their carer members. In the overall network of 50,000 contacts, only 700 still prefer to receive information by post.



wecare.kiwi was established as a pandemic response for carers, older people, disabled people and anyone needing a hand or a listening ear during COVID-19. It is being expanded to connect people as a longer-term goal to reduce the isolation many carers are experiencing.



The [Are you a Young Carer?](#) booklet includes information on what young carers do, what it is like to be a young carer, and tips and resources to support young carers.

EDUCATION & TRAINING

Accessible, affordable technology is providing new pathways to learning, sharing and connecting for carers. COVID-19 accelerated the use of and interest in these tools, with many carers now familiar with Zoom as a way to connect, for example.

Through [CareWise](#), carers learn about their education and training options including new state-funded programmes that will benefit them financially and help them become more knowledgeable about caring.

Carers NZ's CEO publishes [Family Care](#), a quarterly magazine that is widely read in New Zealand (75,000+). It has become a trusted source of information and support ('a pillow at my back', as described by one carer) since 1996. A global Family Care World product (e-only) is being considered.



Helping carers understand their rights and choices (in elections, for example) is a function of Carers NZ's regular information campaigns.

OPPORTUNITIES



Education for carers to support them informally in their role is not systemically available in New Zealand. Although it has been a priority in past Carers' Strategy Action Plans, changes of government have precluded the development of a nationwide, consistent learning programme for carers.

Carers crave in-depth coverage about topics of intense interest to them, such as respite and payment. Work is underway to enhance media and communications to deliver rich content to carers. This will include a podcast hosted by Carers NZ to begin in 2021.

The first carers conference in some years was postponed due to COVID-19. There is a need to explore new ways to host gatherings of carers, and to participate in events hosted by others. COVID-19 has forced these to happen more quickly than they might have been pre-pandemic.

INNOVATIVE CARER PRACTICES



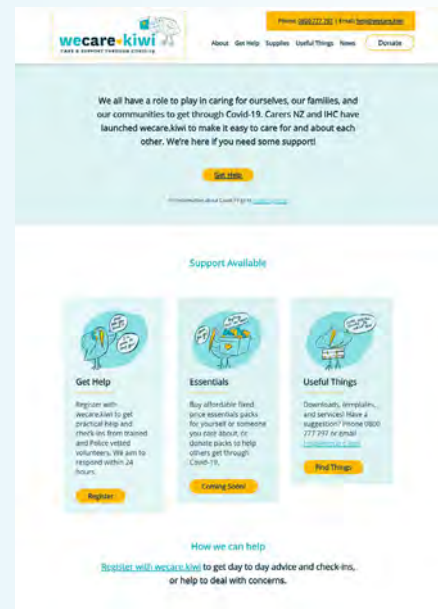
Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN NEW ZEALAND

[wecare.kiwi](#) Carers NZ partnered with a number of non-government organizations (NGOs) to develop wecare.kiwi as an immediate response to the pandemic outbreak. This user-friendly online information source allows carers, people living alone, people with disabilities or chronic conditions—anyone feeling vulnerable—to register at the website for check-ins, practical help and fun uplifting giveaways.

Hands-on support is available via partner charity IHC's nationwide network of police-vetted volunteers (more than 3,000). [IHC](#), New Zealand's oldest and largest charity, used some of its pandemic funds from public giving to support deliveries of treats and fun items to help people get through the initial lockdown period.

Carers NZ is continuing wecare.kiwi with IHC longer term to help isolated carers connect with each other, find friends and local fun events, and to participate in Zoom webinars. A podcast for carers as a wecare.kiwi service is currently in the planning stages.



Carers New Zealand (established in 1995) is the country's peak body supporting family, whānau and aiga carers. It assists a direct network of 50,000+ carers and partner organisations, and acts as the ongoing Secretariat for the NZ Carers Alliance of almost 50 national not-for-profits.

Collectively, Alliance members represent tens of thousands of New Zealand carers spanning age groups, ethnicities, mental health, disability, palliative care and long-term chronic conditions.

Current priorities for Carers NZ and the Alliance are fair, accountable and nationally consistent systems for respite, continence support and payment for carers, and valuing of carers in emerging flexible funding models. Ensuring support for working-age carers and young carers are further priorities.

Special thanks to Laurie Hilsen, CEO Carers NZ, who provided expertise, answered questions and participated in the review of this chapter.

SOURCES:

- New Zealand Ministry of Health. [Website](#).
- New Zealand Ministry of Social Development. [Website](#).
- Parliamentary Counsel Office. New Zealand Legislation. [Website](#)
- Sapere. [Website](#).

In Spain, the term 'carer' is most frequently used. Carers provide care to a spouse or relative who is connected by blood, affinity or adoption, up to the third degree of kinship, who have lived together for at least a year. (Law 39/2006)



POPULATION DENSITY..... 94 per sq km*
POPULATION URBAN 80.3%*
MEDIAN AGE 44 years**
TOTAL DEPENDENCY RATIO..... 52.4***

* [Worldometer](#)

** [Eurostat 2019](#)

*** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64) in 2020.
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



SPAIN

7,000,000¹ CARERS
14.9%² OF POPULATION

¹ OECD, Colombo et al., 2011.

² Spain 2020 population: 46,759,337 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



SPAIN

LEGISLATION

Spanish legislation on the Promotion of Personal Autonomy and Attention to People in a Situation of Dependency ([Law 39/2006](#)) recognises the status of a carer.

Some of the country's autonomous communities (e.g., [Andalucía](#), [Galicia](#), [Valencia](#), etc.) have expanded on the scope of the national definition to adopt more progressive definitions that include informal carers/non-professional caregivers who provide care to someone outside of the family. This is to ensure that the needs of isolated people with a dependency or people living in rural areas, for example, are met.

There is a strong moral obligation of family to provide 'informal care'. The model is female dominated, informal and time intensive. Recognition of this work and of the caregivers is derived indirectly depending on the entitlements of dependent family members. Care recipients are 'persons in situations of dependency' or 'dependent people'.

Caregiving is referred to as 'non-professional care', the attention paid to people in situations of dependency ([Law 39/2006](#)) at home, by the family or its surroundings. Those providing the care are not linked to a professional service.

[Dependency is defined](#) as Grade I – moderate dependency, Grade II – considerable dependency, or Grade III – severe dependency.

RECOGNITION

There is no national recognition or appreciation day specific to caregivers.

The [National Alzheimer's Congress](#) is aimed at both family caregivers' and professional caregivers' need for training. Held every two years, this event has a special relevance for Spanish families and professionals who care for someone with Alzheimer's disease. It provides a unique opportunity to increase knowledge and experiences about all facets of the disease.

OPPORTUNITIES



Implement a comprehensive national carer strategy based on a broad and inclusive definition of carers across the country to help align policy and practice.

IACO is creating awareness of leading evidence-informed practices that support carers from around the world. [LEARN MORE](#)





FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.

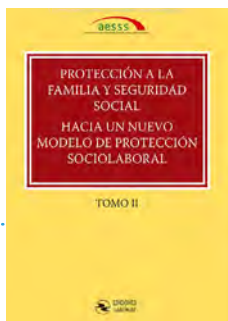


SPAIN

ALLOWANCE

Cash benefits are available for informal care at home and for personal assistance. In addition, a cash benefit is linked to the purchase of services. These cash benefits and their amounts are granted according to the person's degree of dependency and economic resources.

Non-contributory family benefits for children with disabilities: the family of a child under the age of 18 years and with a degree of disability above 33% can expect an annual financial allowance of €1,000. For a dependent over the age of 18 and with a degree of disability of 65% or more, or 75% or more with a need for a carer, the family will receive €4,415 and €6,623 respectively per dependent per year. The dependent child must live in the family home and their annual income must not exceed the minimum wage.



Severe disability pension: This contributory Social Security benefit includes an additional allowance permitting the disabled person (under the age of 65) to pay their carer. The allowance amounts to 50% of the pension ([Article 196.4 of the Social Security Act](#)).

Carer allowance: This payment aims to compensate informal carers for their work and the costs of care in the family setting. The informal carer must be a spouse or family member (up to third degree of relation) living in the same household as the dependent person before the request for support is submitted. The benefit is only granted to non-family members under exceptional circumstances. The allowance is means tested and the amount depends on the degree of dependency of the care recipient.

Financial allowance for personal assistance (Article 19): This benefit allows for the hiring of a personal assistant, for a number of hours, in order to increase the autonomy of the dependent person, irrespective of their degree of dependency. The amount of the benefit depends on the degree of dependency and the economic capacity of the beneficiary.

Financial allowance to contract a service: Allows for the contracting of the service allocated in the Individual Care Programme (e.g., home help services, day/night care centres or residential care services). It is granted when public care services are unavailable and private services must be bought. The amount ranges between €300 and €715 per month, depending on the degree of dependency and the economic capacity of the beneficiary.

Financial benefits for personal assistance and external services are provided directly to the beneficiary, although in practice they often contribute to improving the informal carer's work-life balance.

IACO members
possess a wealth of
knowledge and experience
in supporting carers. [LEARN MORE](#)





FINANCIAL SUPPORT (CONT.)



SPAIN

TAX EXEMPTIONS/CREDITS

The following tax exemptions or tax credits are available for carers:

- Tax credit per child or dependent family member with a disability of 65% or more (Article 60 [Act 35/2006](#)).
- Tax deduction per child or dependent family member with a disability (negative tax). This is a deduction from the tax amount for taxpayers who are employed or self-employed, and who have made social security contributions during the financial year (Article 81bis [Act 35/2006](#)).
- Some autonomous communities also apply tax deductions for disabled family members' expenses. These deductions depend on the taxpayer not surpassing certain levels of taxable income.

PENSIONS

The first year of the long-term leave, which is unpaid, is fully included in the calculation of pension contributions.

Non-professional carers of beneficiaries of the [Dependency Law](#) (39/2006) can sign a Special Agreement with Social Security (article 185 of the [Royal Decree-Law 6, 2019](#)) without having to pay the corresponding social contributions.

The objective of the letter, signed in the vast majority by women, is to ensure that the interruption of the carers' working life to provide care for a dependent person does not penalize their rights to retirement. The protective action of this special agreement concerns situations of retirement, permanent disability, as well as widowhood pensions. It is aimed at persons designated as informal carers in the [Individual Care Program](#) (PIA), prepared by the Social Services of the municipality of residence of the applicant.

When signing the special agreement, the carer can opt for a contribution base that is equivalent to the minimum ceiling of the general scheme - the standard amount selected by the Administration— or a higher contribution base (the difference paid for out-of-pocket) in order to anticipate excessive annual charges.

To subscribe, the carer should not benefit from any full-time Social Security scheme or unemployment benefits. Moreover, the person receiving care should be recognised as being in a situation of dependency by the corresponding Management Body of the Autonomous Community of residence of the applicant, as well as by the Institute for the Elderly and Social Services (IMSERSO), a government agency

OPPORTUNITIES



Reduce bureaucratic hurdles so unpaid carers can easily receive financial support for care recipients.

It is important to note that the combination of cash benefits and benefits in kind is often not possible, except for services designed to prevent situations of dependency, to promote personal autonomy and for tele-assistance.



The **Individual Care Program** is a report prepared by the Social Services corresponding to the applicant's municipality of residence and includes the most appropriate intervention modalities for the person based on the resources provided in the resolution for their grade and level.

The following questions, which are intended to serve as a basic orientation to Community Social Services, focus exclusively on those issues that may be useful to people interested in requesting both the recognition and assessment of dependency situations and the right to different benefits and services contemplated by the System.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



SPAIN

WORK & CARE

There are three possibilities for a carer's leave under the Social Security institutional framework (Ministry of Health, Social Services and Equality, 2015) and [Law 39/1999](#), dated November 5, to promote the reconciliation of work and family life of working people. The law provides the right to reduced working hours. A leave of absence is extended to workers who have to take care of the elderly and the sick, in line with demographic changes and the ageing of the population.

Short-term leave

(Chapter 1 Article 1) – Two days, which can be extended to four if travel is required, in order to care for family members (up to the second degree) regardless of their age, who have suffered an accident or serious illness, hospitalization or outpatient surgery. The leave is fully paid for by the employer.

Long-term leave

(Chapter 6) – Reductions of the working day to care for family members (up to the second degree) due to old age, accidents, serious illness or disability. The reduction can last for up to two years (unless extended by collective bargaining). For public servants, this can be extended for up to three years. This leave is unpaid but the first year is fully included in the calculation of pension contributions. The employee's job is safeguarded for the first year of leave, after which a position of equal professional level is guaranteed.

Reduction of working hours to care for a child suffering from cancer or other serious illness requiring long-term hospitalization

This type of leave is available to parents and enables them to reduce their working hours by up to 50% to care for a child in the mentioned situations. The leave may last until resolution of the illness or until the child reaches 18 years of age.

OPPORTUNITIES



Gather data and launch strategies to support young carers.

Adapt and extend the Spanish legislation—and in particular the short-term leave entitlement—to comply with the right introduced by the EU's [Work-Life Balance Directive](#). The directive includes a caregiver's leave of five days per year and the right to request flexible working arrangements.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



SPAIN

RESPITE CARE

Day care centres (Article 24) aim to improve and maintain the highest possible level of personal autonomy for the individual, support families and carers, and enable work-life balance. Although this service has spread significantly over the last decade, its availability tends to vary among autonomous regions.

Night care centres (Article 24) offer a respite service which, while much less widespread than day care centres, are primarily designed as a support service targeted at carers.

Residential care services (Article 25) provide respite in the form of temporary convalescence stays, holidays and illness, or rest for carers.

Home assistance services (Article 23) can be viewed as a form of support for the carer of people with a high degree of dependency.

Subsidies are also available for home adaptation.

[LEARN MORE](#)

Teleassistance, such as from Tunstall, offers continued contact and support to carers, providing them with the confidence to maintain their role as the care recipient's needs increase. [LEARN MORE](#)

EMOTIONAL & SOCIAL SUPPORT

Many entities, both public and private, offer training courses targeted at family carers of dependent people in many localities. A variety of courses and workshops are available to carers by [autonomous communities](#).

The [One Caregiver – Two Lives](#) programme (Un cuidador, dos vidas), funded by the 'La Caixa' Foundation, comprises a variety of opportunities aimed at supporting family carers, including various training activities.

[Mutual Help Groups](#) (GAM), such as Caregiver Support Groups, are a relatively recent social phenomenon in Spain. They provide opportunities for emotional expression, the exchange of experiences and the development of quality social relationships. Their objective is for carers to provide support for each other as well as material or emotional services aimed at giving relief to the person in question, and to their family members or carers.

OPPORTUNITIES



Recognize respite care nationally as a right and provide more funding to implement respite care in all regions.





INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.

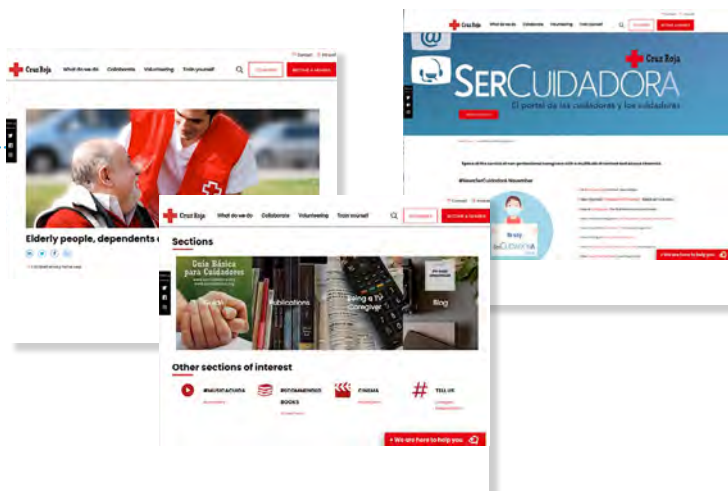


SPAIN

The [Foundation for Research and Training in Health Sciences](#) (Fundación para la investigación en ciencias de la salud) web portal lists a selection of relevant information sources available in Spain and at an international level that are targeted to carers.

The Spanish Red Cross has developed an online information hub for carers, [SerCuidadora/SerCuidador](#), which provides practical information and advice to carers. The hub includes:

- a Care Guide designed and written to provide carers with information about the different aspects of caregiving;
- publications on relevant carer topics;
- SerCuidadorA TV, a series of audio-visual materials providing advice to carers; and
- a blog outlining the experiences of fellow carers.



Training of carers at the regional level is regulated by a resolution to the Dependency Law in 2009. The Ministry of Employment and Social Security Agreement on common accreditation criteria for training and information for nonprofessional carers requires regions to train and assess the skills of all caregivers. [LEARN MORE](#)

The [ALTERNATIVE](#) project (2016–2018), funded under the EU Erasmus+ programme, aimed to enable family carers to acquire detailed knowledge of the different types of disabilities and pathologies related to ageing. Consisting of a partnership between Spain, France, Belgium and Italy the project sought to develop professional practices guaranteeing the well-being and respect of the care recipients as well as developing the skills of carers in order to improve their employability. The outcomes of the projects included:

- a professional reference system;
- a reference system of skills; and
- a training repository.

This training was the subject of an experiment conducted in each of the participating countries with a test group made up of family caregivers. The test covered more than 30% of the total volume of the targeted training (i.e., 240 hours). Small seminars were organised in each country to disseminate the final results of ALTERNATIVE.



[School of Caregivers](#), developed by '[La Caixa](#)' Foundation, provides carers and volunteers with information, techniques and skills on offering good-quality care to people in a situation of advanced disease or at the end of life.

The programme runs on a cycle of nine (face-to-face or virtual) workshops, with a duration of between 1.5 and 2 hours each, aimed at a minimum of 10 people and a maximum of 15. The workshops are led by experts in the different areas covered by the school (i.e., psychology, nursing, physiotherapy and social work). The educational content of the school is structured around three key themes:

- Know (technical content) – Aimed at acquiring knowledge.
- Being (principles and values) – Focussed on recognising affection and motivation (emotions).
- Do (tools and skills) – Oriented to facilitate resources and empower caregivers.

OPPORTUNITIES



Provide support to regions to increase education and training. Implement an integrated approach for providing community support to unpaid carers so they can access community-based services.

INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN SPAIN

Caring for Carers an innovative training programme, developed by the [Cauces Association](#), is a support programme in the Madrid municipality that offers psychological support to the carers of dependent elderly people. The topics addressed by the intervention are organised around four thematic blocks:

- self-knowledge;
- self-acceptance;
- self-appraisal; and
- strategies for change.

The first session is dedicated to increase the knowledge of the group and aims to promote the interpersonal relationships of its members, creating a group conscience and a feeling of belonging that fosters introspection. The innovative dimension of this initiative builds on a methodology that is not limited to the transmission of theoretical knowledge. Instead, it focusses on creating an environment and interpersonal dynamics that facilitate and promote personal development, adaptation to the complex situation of caregivers, the establishment of new interpersonal relationships and cooperative group learning.

Mindfulness for Carers was designed by the municipality of Lleida (Catalonia) to expand on the Municipal Support Program for carers in response to participant requests for continued professional support. The workshop was a pioneering and innovative event based on mindfulness and targeted at carers defined in the programme as 'people who are dependent on dependent family members'. The intent was to support carers in improving their quality of life and ensure proper care for the dependent person.

The objective of the training was to provide methods and strategies to learn how to deal with emotions, reactions and thoughts generated by the provision of care to a dependent person and prevent situations of stress and exhaustion. The workshop, held in April and May 2020, was directed by a psychologist specialized in the practice of mindfulness. It was aimed at caregivers of people recognised with a degree of dependency who had attended the basic training course also offered by the Lleida City Council.



The Spanish Alzheimer's Confederation (Confederación Española de Familiares de Enfermos de Alzheimer y otras Dementias - CEAFA) is a national non-governmental organisation comprised of one autonomous confederation, 12 autonomous federations and six uniprovincial associations that bring together more than 300 local associations with more than 83,130 direct partners. This associative network has 5,419 volunteers and 3,863 workers who care for people affected by Alzheimer's disease and their family caregivers.



Cuidadores Familiares is a group of motivated professionals who understand carers' issues and are committed to being involved in the creation of necessary supports.

Special thank you to Stecy Yghemonos, Executive Director, [Eurocarers](#), for his expertise and review of this chapter.

SOURCES:

- UNECE. (2019). The challenging roles of informal carers. [UNECE Policy Brief on Ageing.](#)
- Law 39/2006, Of 14 December. [Promotion of Personal Autonomy and Care for People in a Situation of Dependence.](#)

In Sweden, the term 'carer' is most frequently used. Carers are family, close friends, significant others or neighbours who provide emotional and practical help, support or care to people who suffer from a long-term illness, disability and/or abuse.



POPULATION DENSITY..... 25 per sq km*
POPULATION URBAN 88.2%*
MEDIAN AGE 41.1 years*
TOTAL DEPENDENCY RATIO..... 61.2**

* Worldometer

** Wikipedia

Ratio of combined youth (ages 0–14) and older (ages 65+) populations per 100 people of working age (ages 15–64) in 2020.
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



SWEDEN

1,300,000¹ CARERS
12.8%² OF POPULATION

¹ Swedish Family Care Competence Centre

² Sweden 2020 Population: 10,107,657 (Worldometer)



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



SWEDEN

LEGISLATION

There is no legislation specific to carers only in Sweden.

The [Social Services Act](#), 1982 covers everyone with care needs irrespective of age and type of disability and assigns the responsibility to the municipalities. From 2009 onwards, it stipulates that municipalities shall offer support to carers but does not explicitly address carers under the age of 18 years.

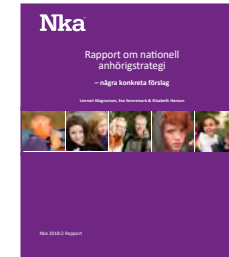
The [Act on Support and Service for Persons with Certain Functional Impairments](#) (LSS) is based on the basic principles of accessibility, influence, participation, self-determination, a holistic view and continuity. The purpose is to promote people's equality in living conditions and full participation in society. The activities must be based on respect for the individual's self-determination and integrity.

From 2010 onwards, the Health Care Act states that health care staff must reach out and provide information and support to children as next of kin, namely children (up to 18 years) with parents who suffer from mental illness, severe physical disability or any form of substance abuse. Health care staff must also support children who have unexpectedly lost a parent or another adult with whom the child permanently lives.



RECOGNITION

In response to the initiative of the [Swedish Family Care Competence Centre](#) (Nationellt kompetenscentrum anhöriga – Nka) and lobbying of [Carers Sweden](#), the Minister of Health and Social Affairs tasked the National Board of Health and Welfare to prepare a national carer strategy (covering carers of all ages) and to provide an initial report (focussing on carers of older people) to the Ministry by the end of December 2020. A further report on other key carer groups is due by summer 2021.



Sweden hosts a variety of conferences and events that provide opportunities to recognise carers and advance policies and programming.

- At the 21st Annual Carers conference in Varberg, West Sweden, May 7–8, 2019, Minister of Health and Social Affairs in Sweden, Lena Hallengren, expressed a wish to work toward a national strategy for carers.
- The 6th Annual International Carers conference in Gothenburg, Sweden, September 3–7, 2015 (co-hosted by Nka and Carers UK), raised awareness of carers, issues on a global level and engaged participants from around the world through films, seminars and workshops. Interviews and photos are available on the [Nka website](#).
- The Annual Carers 2020 Conference was transformed into a digital event due to COVID-19 restrictions. The theme was 'carers at the end-of-life'.

OPPORTUNITIES



Provide a framework for policy development through the establishment of the National Carer Strategy.

Participate in the major ongoing health reform, '[God och Nära vård](#)' (good and close care), which is a move to provide integrated, people-centred health care focussing on primary health care and shifting health care to people's own homes. This will likely result in an increase in care provided by carers. In response to stakeholder consultation, NKA has provided a detailed submission based on feedback from carers and their organisations and other stakeholders.

Ensure that carers are included as much as possible within the planned new legislation, 'Sustainable Social Services', a new Social Services Act, which was recently out for formal review with invited experts and stakeholders including Carers Sweden and Nka.

Nka is co-hosting the third [International Young Carers Conference](#) together with Eurocarers that will take place online on May 3–6, 2021. The conference targets multiple stakeholders, including young carers themselves and their organisations and policy-makers.

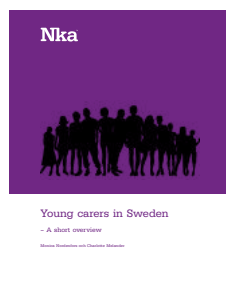


CARER RECOGNITION (CONT.)



SWEDEN

YOUNG CARERS



Young carers were generally not recognised until 2014, when two surveys were conducted identifying the estimated number of children providing care and their need for support. In 2017, Nka produced an [overview of young carers in Sweden](#). The report suggests that work to support young carers needs to be further developed

and coordinated with education, health care and social services.

[Me-We](#) (Psycho-social Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe) is a European research and innovation project, funded through the [EU Horizons Program 2020](#). The project (2018–2021) is coordinated by Linnaeus University and brings together prominent universities, research institutes and civil society organisations from six different European countries (Sweden, the Netherlands, Italy, Slovenia, the UK and Switzerland) and [Euro-carers](#), the European network representing informal carers. Me-We aims to improve the mental health and well-being of adolescent carers by strengthening their resilience in order to have a positive impact on their mental health and well-being and to mitigate the negative influence of psychosocial and environmental factors in their lives.



Based on the work to date and the current policy environment, [recommendations for Swedish policy makers](#) from the Me-We project include:

- Conduct further research on the profiles and needs of young carers.
- Disseminate good practices and share them with other countries.
- Include young carers in the European Youth Strategy and EU agenda on higher education.
- Listen to ensure meaningful participation of young carers.
- Leverage available tools, such as the [European Semester](#), [European Pillar of Social Rights](#), [European Structural and Investments Funds](#), [European Youth Strategy](#), [European agenda on higher education](#), [European Platform for Investing in Children](#), and [Youth Guarantee and Open Method of Coordination](#) to promote the development of integrated approaches for the identification, support and social integration of young (adult) carers across Europe.

The initial Me-We report also notes that in Sweden, 7% of children aged 14–16 years carry out substantial amounts of caring.





FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



SWEDEN

ALLOWANCE

Home care allowance (Hemvårdsbidrag) (also referred to as relatives' allowance, nursing allowance or paid relatives) provides monthly financial compensation for care recipients who are receiving care at home. A carer is defined as a family member, relative, good friend or neighbour. The allowance can be granted if the person providing the care has significant additional work and if the care provided is not of the type that is normally given to help each other within the family. It is expected that the care recipient uses the allowance to compensate the carer.

This grant is not available in all municipalities. The rules for who can receive the grant also vary among municipalities, as do the size and name of the grant. A benefits officer decides whether the applicant receives the grant.

The home care allowance is not taxable if it is paid to a carer with whom the care recipient lives. However, if it is for a person living outside the household, the carer must declare the income for taxation purposes. The grant does not cover social benefits.

When no longer needed, the allowance stops at the end of the next month. Payment can be authorized in lower amounts if the care recipient participates in, for example, day activities or short-term housing, or short-term care and only needs care when at home. The home care allowance cannot be paid retroactively.

Carers Allowance is payment made by the municipality in which a family member does the care work. The compensation is the same as for those employed to deliver home-help. This type of allowance is less common than in previous years. There are arguments that it leads to carers, particularly those with an immigrant background, being tied to the home and remaining far from the labour market (Sand, 2016).

Benefit for care of closely related persons (Närståendepenning), or Compassionate Care leave, is payment made to carers who are taking time away from work to care for a close relative who is seriously ill (i.e., has a life-threatening condition). The compensation is normally a little less than 80% of the carer's sickness benefit qualifying income, which is often the same as the annual work-related income, but there is a maximum limit.

The benefit can be taken as partial days and is paid for up to 100 days for each care recipient. The days can be shared between carers, but the benefit cannot be paid to several carers for the same period of time.

The care recipient must consent to the care by completing the paperwork. If the person cannot provide consent, the physician must complete the form and note that the person is unable to consent. [LEARN MORE](#)

Municipal general benefits in the form of a carer benefit are provided in approximately 55 municipalities in Sweden. Individual needs-assessed financial support to carers is only provided in approximately 25 municipalities in Sweden. [LEARN MORE](#)

PENSION CREDITS

All Swedish citizens are entitled to a national retirement pension after they retire. Most people employed in Sweden also receive an occupational pension based on contributions made by their employers.



OPPORTUNITIES



Standardize of services across all 290 municipalities to ensure all Swedes have access to equitable support.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



SWEDEN

WORK & CARE

The employer is legally bound to hold the employee's position open while they are on formal Compassionate Care Leave (receiving the benefit for a closely related person).

'Family' is broadly defined to include neighbours and friends. An [analysis](#) in 2018 showed that the number of people cared for by a person receiving compassionate care allowance (and therefore taking a leave from work) increased from 5,300 in 1996 to 14,700 in 2017. Most recipients are women (70%), while only 30% are men.

OPPORTUNITIES



Continue to build on the earlier work carried out by Nka and Carers Sweden (inspired by Carers UK's Employers for Carers' Forum) to engage with employers to raise awareness of working carers and provide resources for support.

Nka is an invited member of Corporate Social Responsibility Sweden's working group on Sustainable Working Environment reporting on working carers issues. [LEARN MORE](#)

The European Union ([EU Worklife Balance Directive](#)) came into force on August 2, 2019. This directive aims to improve families' access to family leave and flexible work arrangements. Measures under the directive include:

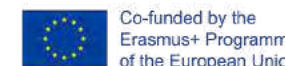
- The introduction of paternity leave: Under the directive, fathers must be able to take at least 10 working days of paternity leave around the time of birth of their child, compensated at least at the level of sick pay.
- Changes to parental leave: Two out of the four months of parental leave are non-transferable between parents and are compensated at a level that is determined by the member state.
- The introduction of carers' leave: Workers providing personal care or support to a relative are entitled to five days of leave per year.
- Extending the right to request flexible working arrangements to carers and working parents of children up to eight years old.

All EU member states (MS) have until August 2, 2022, to agree on how this directive will be translated into national law in their own countries. For example, Sweden and other MS can decide if the leave is paid or not and if the leave is longer than five days. They might also limit the duration of the flexible working arrangements. Within the [Ministry of Employment](#), ongoing work is currently taking place to determine how to reach the EU goal within Swedish legislation.

EDUCATION & CARE

The [EDY-CARE](#) project (2018–2020) was coordinated by Linnaeus University and Nka with the aim to empower teachers and other school staff (e.g., school nurses, psychologists, social workers, management) in upper secondary education (ISCED-3 level) to recognise adolescent carers age 16–19 years in class and maximise their learning opportunities, while ensuring their social inclusion. The concrete outputs from EDY-CARE included:

- developing an assessment to help teachers and school staff identify young carers;
- developing and testing a package of resources that includes a checklist of educational strategies, didactical approaches, as well as organisational adjustments that schools can take to facilitate young carers and support them in their scholastic career;
- producing a handbook that provides guidelines and recommendations on how teachers and school staff can best work with young carers; and
- creating a massive open online course (MOOC) for training teachers and school staff on the young carers' phenomenon, their needs and preferences.





HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



SWEDEN

RESPITE CARE

The range and extent of respite care varies among municipalities with some municipalities, offering more flexible services than others.

Almost all 290 municipalities offer family carers in-home respite care during the day free of charge. This is subject to a formal assessment of the care recipient's needs by a Needs Assessor so that the respite care is allocated to the person in need of care.

Other forms of respite care may include '24h instant-relief' (or drop-in services) or, in some cases, weekend breaks (short-term accommodation, 'växelvård'). Care recipients can use the short-term accommodation on a regular basis if necessary. As an example, 'shift care' enables the care recipient to live every other week in short-term housing and every other week at home.

Some municipalities have special departments that only offer short-term housing. In other municipalities, there are special short-term breaks in local nursing homes. An Assistance Officer decides on placement in short-term housing.

In recent years, some municipalities have created special assisted living facilities. These facilities can also act as a support for carers who need temporary relief. Access to these facilities can sometimes be arranged directly with the manager/owner and does not always need a decision from an Assistance Officer. Criteria differ across municipalities as they each have different rules for the length of stay and cost.

Relief through day activities or day centres means that care recipients can take part in a daily activity outside the home during one or more days of the week. This gives carers the opportunity to relax and do their own activities. Special day activities for people with dementia and for people with other specific disabilities are also often provided.

Some municipalities offer stays at spa-hotels and arrange for care of care recipients for one or two days. Mixed strategies combining different forms of respite are complementary. [LEARN MORE](#)

Approximately 113 municipalities (out of 290 Swedish municipalities) offer '[Feeling/keeping well' days/activities](#) (Må bra aktiviteter/dagar) via the municipality's dedicated carer advocate together with the local carer organisation and other organisations. Carers can take part in wellness activities that may include physical exercises, Nordic walking, yoga, relaxation, water gym, tactile massage, mindfulness, and spa and leisure activities. The frequency, duration and type of activities offered vary from one municipality to another. Sometimes these activities are offered to the carer while their care recipient receives respite care services. [LEARN MORE](#)

Many carers have expressed an interest in having a regular health check-up. However, only approximately 16 municipalities offer carers a health check-up by qualified staff, often at a local health centre. [LEARN MORE](#)





HEALTH & WELL-BEING (CONT.)



SWEDEN

EMOTIONAL & SOCIAL SUPPORT

- 224 municipalities offer individual supportive conversations to carers.
- 170 municipalities offer family supportive conversations.
- 197 municipalities offer carer support groups.
- 103 municipalities offer bereavement support.
- 158 municipalities provide carer cafés and drop-in meeting places for carers.

Before COVID-19 there were very few online forms of online emotional and social support for carers.

[LEARN MORE](#)

Many municipalities employ carer advocates advisors to provide direct support to carers and, in some cases, to have a more strategic function by being responsible for developing carer support at a municipality level. There are indications that the number of carer advocates is being reduced in some municipalities, and likewise fewer have a strategic function. This is especially the case during the COVID-19 pandemic. More well-developed municipalities offer good examples of carer advocates working in partnership with local carer organisations to offer support to safeguard carers' health and well-being, often at carer cafés and meeting/drop-in centres.



OPPORTUNITIES



Continue to lobby politicians at local and regional levels to maintain the role of carer advocates.

Continue to educate all health and social care professionals to recognise and work in partnership with carers and school staff.

Follow up and evaluate the various supports currently being offered to ensure that they are effective in meeting the needs and preferences of a variety of carer groups and situations (Hanson, 2019).

IACO members are working collaboratively and independently to raise awareness of carers, identify and disseminate best practices and enhance carer well-being.





INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



SWEDEN

INFORMATION

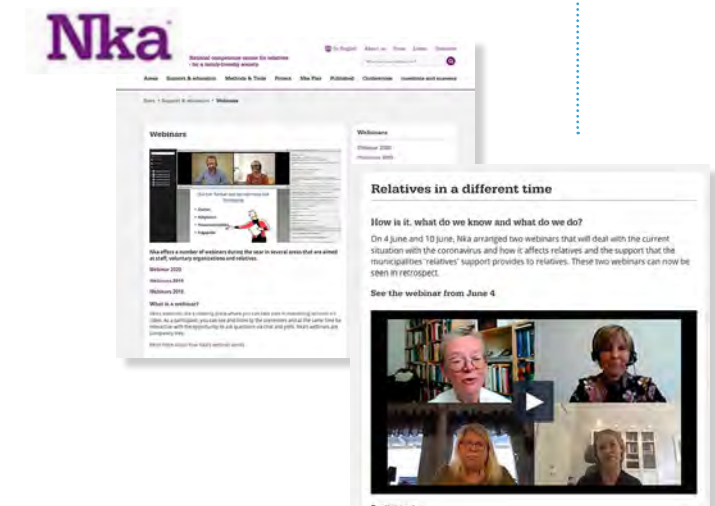
Carers Sweden has an online [Carer Handbook](#), developed by and for carers, which provides a range of information and education. The Association also regularly updates their website and social media with information.

Nka also has a dedicated website that provides a variety of information. [LEARN MORE](#)

Carers Sweden, together with [Helsjön folk high school](#), offers an in-depth [course for carer advocates](#). The aim is for participants to analyse the meaning of informal care from different perspectives, learn about and reflect on legal issues in their work, and learn about methods of conversation/communication. The course provides an educational approach in order to be able to effectively meet carers in different situations. It also encourages participants to reflect on their own attitudes and values, and consider their role as carer advocates from different perspectives.



Nka has a range of [web-based education courses and training](#) in the area of carers, informal care and carer support that are also targeted at different groups of carers.



OPPORTUNITIES



Further develop online sources of support. Previous work by Andersson (2017) regarding working carers, the survey on carer support by [Takter et al \(2019\)](#) and Nka's population survey (2018) revealed that there is further significant potential for information- and communication-based solutions and welfare technologies to benefit carers. Further, working carers in particular are open to new and more flexible forms of support.

INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN SWEDEN


Blended Learning Networks are heterogeneous Communities of Practices that include individuals of various backgrounds and experiences who share a common interest and work together to achieve a common goal. Focussing on an agreed-upon issue, participants learn from each other, while getting to know and respect members of the network. Beginning in 2008, over 150 Blended Learning Networks (BLNs) have taken place in municipalities throughout Sweden. This unique approach is an important part of building awareness of carer issues and co-creating solutions. Nka uses BLNs to help participants successfully gain awareness and understanding of relevant research and obtain practical, 'know-how' and information from carers' unique experiences.

Feedback from BLNs includes the following:

- Carers felt they were more equal partners in the discussions and deliberations and actively listened to by other stakeholder participants.
- In many municipalities, BLNs have acted as important advisory groups to develop family care support.
- BLNs have helped increase awareness of carers, issues and allowed for more focus on preventative strategies.
- BLNs have engaged companies that actively support working carers.

BLN meetings are documented and lead to communications materials, educational content and topics for study circles among key stakeholders' groups. This leads to change at local and regional levels by acting as a stepping stone for further work with innovative policies and practices.



 **ANHÖRIGAS
RIKSFÖRBUND** **Carers Sweden** (established in 1996) is a non-profit national carer organisation consisting of over 60 local associations together with other supporting organisations and individual members. It supports all carers irrespective of the age, gender or diagnosis of the care recipients.

Nka **Swedish Family Care Competence Centre** (Nationellt kompetenscentrum anhöriga NKA) (established in 2008) is commissioned by the Ministry of Health and Social Affairs via the National Board of Health and Welfare Sweden. NKA is a centre of excellence in the field of family (informal) care. Carers Sweden (Anhörigas Riksförbund) is one of six founding partners of the centre partners.

Special thanks to Elizabeth Hanson, Professor Linnaeus University, Dept. Health & Caring Sciences; Principal Investigator, Coordinator, EU H2020 ME-WE project; Research Leader, Swedish Family Care Competence Centre, who provided expertise, answered questions and participated in the review of this chapter.

SOURCES:

- Andersson, S., Erlingsson, C., Magnusson, L., Hanson, E. (2017). The experiences of working carers of older people regarding access to a web-based family care support network offered by a municipality. *Scandinavian Journal of Caring Sciences*, 31, 487-496.
- Eurocarers. [Towards carer-friendly societies. Eurocarers country profiles \(2020\)](#).
- OECD. (2011). *Help wanted? Providing and paying for Long-term care*. Chapter 4, Policies to Support Family Carers.
- Johansson, L. (2004). *Eurofamcare, National Background Report Sweden*.
- Sand, A.-B. (2016). *Anhöriga som kombinerar förvärvsarbete med anhörigomsorg, uppdaterad version (Family carers combining working life with care and support for a family member, updated version) (Kunskapsöversikt 2016:3): Nationellt kompetenscentrum Anhöriga (Swedish Family Care Competence Center)*.

In Taiwan, the term 'family caregiver' is most frequently used. Family caregivers are family members who take care of a family loved one and provide daily long-term care without compensation.

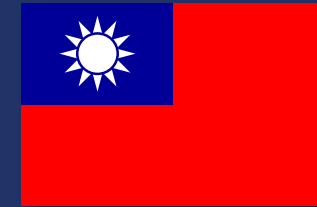
POPULATION DENSITY..... 651 per sq km*
POPULATION URBAN 78.9%**
MEDIAN AGE 40.10 years**
TOTAL DEPENDENCY RATIO..... 62.4***

*National Statistics, the R.O.C.Taiwan (Oct 2020)

**Worldometer

***Wikipedia.

Ratio of combined youth population (ages 0–14) and elderly population (ages 65+) per 100 people of working age (ages 15–64) in 2020.
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



TAIWAN

1,400,000+¹ CARERS
4.5%² OF POPULATION

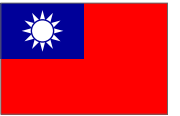
¹ Taiwan Association of Family Caregivers, 2007 survey

² National Development Council, R.O.C.Taiwan Data Query (23,571,137)



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



TAIWAN

LEGISLATION

The core value of 'filial piety' expects adult children to take care of their aging parents in Taiwan.

Both the Common Law and the Criminal Law require children to support their elder parents financially or emotionally. The Criminal Code assigns children convicted on charges of parent abandonment to prison terms of six months to five years (under article 294 of Chapter 5, Crimes of Abandonment) for failing to fulfill the obligation to look after their parents. An [exclusion in the Criminal Code](#) sets forth circumstances exempting children from criminal punishment in situations where they have been abused, abandoned or neglected by their parents.

The [Long-term Care Plan 2.0](#) was introduced by the Ministry of Health and Welfare in 2017 in response to the country's aging population and changes in family structure that have resulted in fewer caregivers. This Plan explicitly recognises the need to better support family caregivers, a goal being 'To achieve aging in place...and to establish community-based care to improve the quality of life for care recipients and their caregivers'. The plan established a three-tiered service delivery system:

- Level A agencies, or community-based service centres, are responsible for preparing care plans and linking services for individuals with cognitive impairment and/or disability.
- Level B agencies are connected to Level A agencies and are responsible for delivering long-term care services.
- Level C agencies, neighbourhood long-term care stations, are responsible for providing preventive and disability delay services.

The plan provides services including home care, day care, transportation, meals, purchase and rental of equipment, home accident-proofing, home nursing care, home and community rehabilitation services, respite care, caregiver support services and service centres for family caregivers, and training to prevent or delay the onset of disabilities (e.g., swallowing and muscle strength training). [LEARN MORE](#)

The [Long-term Care Service Act](#), implemented in June 2017, addresses support for family caregivers by including them as recipients of the home care service offering. Specifically, Article 9.1.(4) focusses on family caregiver support services as fixed-location and home support services provided to family caregivers. Article 13 describes the scope of support services provided to family caregivers as:

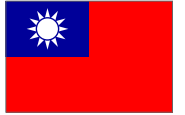
- 1 Provision and referral of relevant information
- 2 Long-term care knowledge and technical training
- 3 Respite care services
- 4 Emotional support and referral to group services
30 days a year
- 5 Other services that help promote the capability of family caregivers and their life quality. [LEARN MORE](#)



Taiwan became an 'aging society' in 1993, became an 'aged society' in 2018 and is projected to become a 'super-aged society' in 2025 (when 20% of the population will be 65 years and older).



CARER RECOGNITION (CONT.)



TAIWAN

RECOGNITION

Family Caregiver Day takes place on the fourth Sunday in November; the entire month of November is recognised as a time to appreciate caregivers in Taiwan. During [Family Caregivers Appreciation Month](#), the Taiwan Association of Family Caregivers (T AFC) hosts a series of activities to pay tribute to, recognise and support family caregivers. Examples include concerts for caregivers and the Smart Caregivers Award, which recognises those who can maintain the well-being of both the caregiver and care recipient by using external resources or call for help to balance caregiving, working and life. It is a preventative approach to avoid care tragedies due to caregiver burnout.

TACF is the first non-profit organization dedicated to advocating for family caregivers' rights in Taiwan through news releases and press conferences. BNP Paribas Cardif TCB Life Insurance Co., Ltd., is one of the sponsors. It is committed to supporting TACF's causes and pilot projects, such as providing a respite academy, carer cafés, re-employment assistance, carer-friendly workplaces, concerts for caregivers, a broadcasting mobile van and a carer book club.



TAIWAN
ASSOCIATION
OF FAMILY
CAREGIVERS



OPPORTUNITIES

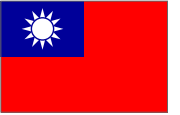


Through increased awareness of family caregivers, better supports will be available. More caregivers will be comfortable accessing family caregiver support services, including case management, home care technique and training, respite service, support groups, stress reductions activities, counselling, and telephone reassurance.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



TAIWAN

In 2017, long-term care was added to Taiwan's national health insurance (NHI), which was implemented in 1995. NHI is a government administered programme under the Ministry of Health and Welfare (MoHW). Every citizen is covered by National Health Insurance. Those with [catastrophic illnesses or rare diseases](#) do not need to pay a co-payment for outpatient or inpatient care.

CARE ALLOWANCE

A [Special Care Allowance for Middle or Low-income Senior Citizens](#) is available to one family caregiver aged at least 16 years and no more than 65 years living in the same municipality as the care recipient and not working full-time at another place of employment. The care recipient must be receiving the [Living Allowance for Mid-or Low-income Senior Citizens](#). The caregiver is eligible for a NT\$5,000 (US\$167) allowance for each household.

TAX BENEFIT

Per [Deloitte Taiwan](#), amendments to the Income Tax Act (ITA) in 2019 targeted the needs of low- and middle-income families caring for physically and/or mentally disabled family members. Taxpayers are eligible for a special tax deduction of NT\$120,000 (US\$4,000) for long-term care if they are deemed disabled in accordance with guidelines issued by the Ministry of Health and Welfare. They are not required to submit any supporting documentation for expenses, whether they hire live-in caregivers, pay for care for physically and/or mentally disabled family members at a long-term care facility, or personally care for such family members.



IACO members are working collaboratively and independently to raise awareness of carers, identify and disseminate best practices and enhance carer well-being.

Once seen as a personal and private matter in family life, unpaid caregiving has become one of the most important social and economic policy issues worldwide.

OPPORTUNITIES

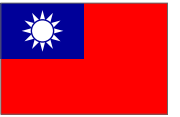


1. Extend the Special Care Allowance for all caregivers.
2. Pay reasonable compensation to family caregivers.
3. Develop and implement a self-direct policy for caregivers.



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



TAIWAN

WORK & CARE

Some companies and employers are interested in building family caregiver-friendly workplaces. Under the [Act of Gender Equality in Employment](#), employees are entitled to up to seven days of family care leave per year to take care of family members. However, the benefit falls short of providing a more extended period for family caregivers to arrange a care plan and services for their family member.



EDUCATION & CARE

There is no official resource to support young caregivers in Taiwan. However, it has been long recognised that the impact of caring activities on young caregivers differs from the impact on adults. Furthermore, the caring tasks and experiences involved also distinguish young carers from other non-caring children and young people.

Policy development is underway to:

Equip schools as essential points to identify young caregivers.

Give young caregivers the right to ask for their needs to be assessed and fulfilled.

Adopt a whole-family approach working with young caregivers.

Define the scope of young caregivers.

[LEARN MORE](#)



OPPORTUNITIES



Family caregivers need job-protected leaves in order to care for family members. As interest in and awareness of the importance of caregiving increases, there is an opportunity to advocate for a long-term care leave, that provides up to 30 days paid leave and 150 days unpaid leave.

Family caregivers should be provided with flexible work arrangements in the workplace.

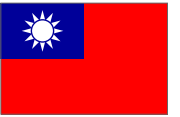
Work to build caregiver-friendly workplaces should be scaled and spread across the country in various companies, with capacity-building in human resource departments.

Work with schools needs to be urgently undertaken to identify young caregivers within the school system and acquire a better understanding of their needs.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



TAIWAN

RESPIRE CARE

Respite services include home, community and institutional respite.

Caregiver respite is based on the condition of the care recipient as indicated by the disability severity level. Under the Long-term Care Plan 2.0, the recipient is assessed across eight disability severity levels, Level 1 being the lightest (i.e., frail) and Level 8 being the heaviest (i.e., bed-ridden).

For family caregivers taking care of recipients at disability severity Levels 2–6, the quota for respite services is roughly equivalent to 14 days of respite service at an institution; for disability severity Levels 7–8, the quota is 21 days. There is a co-pay requirement of 16% for average households; 5% for household of medium- and low-income; and no payment for low-income households.

Recognising that family caregivers need to be independently assessed for their needs, in 1998 TAFC introduced [free respite](#) when caregivers participate in stress reduction activities hosted by the Association. Today, caregiver resource centres across the country provide activity-based respite supported through government and private funding.

MENTAL & SOCIAL SUPPORT

The Ministry of Health and Welfare has been working with professional organisations to set up consultation hotlines since 2008 to provide counselling services for caregivers. It has also worked to establish linkages to relevant community resources to provide support services to family caregivers. As of the end of 2020, the Ministry had established 105 Family Caregiver Support Service Locations. Services include:

- case management;
- care technique instruction;
- care technique training;
- psychological counselling;
- support groups; and
- stress-relieving activities.



TAFC provides a family caregiver hotline, support groups and stress reduction activities through government funding and private donations. Caregivers calling for mental and emotional support are assessed using the [Caregiver Burden Index Scale](#), adapted and adopted by TAFC. Where there is evident emotional burnout or family issues as indicated by a score of 14 or higher, the caseworker will offer counselling if qualified or refer the caregiver for professional help. During the counselling, the caseworker does the case management and coordination; the psychologist/therapist provides up to eight counselling sessions. Both the caseworker and psychologist/therapist will have three meetings to evaluate the outcomes and progress.

The [Caregiver Burden Index Scale](#) is an evidenced-based tool that can be self-administered or used by support personnel. There are five domains assessing the person's perceived level of emotional, physical, economical, relationship and time-management burden.

A score of 14–25 is cautionary and indicates evidence of stress. The caregiver is advised to seek strategies to reduce their stress.

A score of 26–42 shows that the caregiver is heavily burdened and should seek professional help immediately.





HEALTH & WELL-BEING (CONT.)

Telephone reassurance is an ongoing follow-up service by social workers or trained volunteers who provide a monthly telephone call to caregivers to make sure their emotional and physical status is stable. Caregivers can use this opportunity to chat, vent and talk to someone when their social connections may be limited due to the intensity of their caregiving responsibilities.



Calling elder care planning and family meetings can be difficult. TAFC launched an online step-by-step tool to help carers prepare for a family meeting, including assessing needs, gathering information, creating agendas and making plans. The intent is for caregivers to use this tool to open conversations regarding care plans, expectations and clarity about roles. The goal is to reduce unnecessary caregiving lawsuits. TAFC is also working on using this approach and model of care planning in family court.

IACO has established six guiding principles to improve carers' lives around the globe.

[LEARN MORE](#)



TAIWAN

OPPORTUNITIES



The culture of accompanying family members when they need to be admitted to hospital for treatment has existed for a long time in Taiwan due to a nursing workforce shortage. During the epidemics of SARS and COVID-19, when caregivers have not been allowed to accompany their family member to hospital, it has become apparent that the Taiwanese medical system is heavily reliant on family caregivers to provide care. It is time to promote a Skilled Mixed Nursing Care Model in hospitals to decrease the number of family members involved with care when someone is hospitalized.

Continue and increase communications about the many resources now available to support family caregivers.

Notwithstanding the gains in services, particularly with the introduction of LTC 2.0, too many family caregivers suffering from extreme burnout choose to end their life and that of their care recipient. TAFC monitors these tragic events and, through case studies, works to alert public and professional stakeholders of the potential for the direst outcome. The Association continues to advocate for better supports for families.

Provide emergency relief for ill caregivers. Changes in family structure have resulted in fewer caregivers in the family. When a caregiver gets sick, there is no one to care for their loved one. TAFC is working with various charity groups to fundraise immediate financial support for ill caregivers.

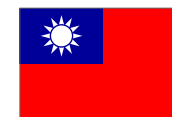
Build on TAFC's work with private sector companies to increase recognition of the needs of family caregivers.

The Association hosts long-term care preparation classes on-site in the workplace.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



TAIWAN

The number of caregiver resource sites and centres that provide services to caregivers is increasing across the country. In 2020, there were 105 Caregiver resource sites and centres throughout Taiwan.

There is a focus on developing integrated dementia care centres for caregivers to receive information and other support services. In addition to providing services, the centres also are mandated to implement dementia literacy public education. This awareness helps people with dementia and their caregivers who are often stigmatised because of the condition.

To help people better understand and navigate LTC 2.0 services, TAFC has launched an [online programme](#) to calculate the cost and subsidy of LTC services. The users select options including personal status, level of care, residence and use of foreign care worker to arrange the services that fit their needs. The online calculator allows the user to calculate their long-term care subsidies and options to choose home-based or community-based care services.

TAFC designs and organises annual training, workshops and case studies for caseworkers in caregiver resource sites and centres to understand the family caregiver's needs and provide support services. In addition, TAFC:

- is active on social media (e.g., Facebook, Line, websites), which are used to support distance learning for potential caregivers;
- has an active [Caregiver YouTube channel](#) to share personal caregiving stories, introduce LTC services and resources and host an online carer book club;

- collaborates with nine coffee shops as LTC information centres to provide respite throughout Taiwan; caregivers go to these coffee shops, fill out a questionnaire verifying their caregiving status and then can enjoy 10 cups of free coffee per year. Coffee shops participate in this effort as part of their corporate social responsibility;
- trains volunteers to become long-term care preparation class lecturers (LCPCL) so they can be an effective resource for caregivers by helping them to understand current LTC information and services; LCPCLs serve at community fairs, events and coffee shops to increase public awareness;
- designs and develops online tools for [navigating LTC services](#) and holds [caregiver family meetings](#).

OPPORTUNITIES



Work on developing online courses for caregiving caseworkers and LTC professionals to gain awareness, knowledge and skills to work with family caregivers.

IACO increases awareness and understanding of the growing number of carers worldwide. IACO facilitates international collaboration by bringing together countries from around the globe that advocate for family carers.



INNOVATIVE CARER PRACTICES



Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN TAIWAN

The Taiwan Association of Family Caregivers (TAFC) is building awareness and empowering local communities to become actively involved in recognising, supporting and connecting carers. Started in 2017, **Carer Cafés** are community-centric, locally operated and supported initiatives across Taiwan that aim to:

- improve identification of caregivers and help carers recognise their own needs;
- increase awareness of, and referral to, long-term care resources and support services in the community;
- offer caregivers a space to take a short 'break';
- help caregivers re-enter the workforce after the caring journey; and
- cultivate social responsibility in supporting caregivers throughout the community.

Building on the concept of a sharing economy, TAFC adapted this unique strategy to address carers' needs, including identification and support. Through mutually beneficial partnerships with local coffee shops, TAFC uses a variety of tactics to reach out to and guide caregivers and encourage them to seek information and support that can improve their health and well-being. The partnerships with the community coffee shops are sustained in part by TAFC, which actively sources funding through corporate sponsors, such as the Taiwan Cooperative Bank.

The entire country has been impacted and there are now more than 100 Caregiver Cafés in Taiwan. TAFC Carer Cafés were identified as a global Innovative Carer Practice in 2018 by the International Alliance of Carer Organization. [LEARN MORE](#)



Taiwan Association of Family Caregivers (TAFC), (established in 1996) is the first non-profit organisation dedicated to advocating for family caregivers' rights in Taiwan. TAFC has achieved many milestones, including ensuring publically-funded respite services in 2007 and mandating caregivers' benefits in the National Long-term Care Service Act in 2015.

TAFC supervises a national network of services, including education, support groups, counselling and case management. TAFC has individual and organisational members from multiple disciplines working together to continue advocating for economic security, work/life balance and health management for family caregivers in the future.

Special thanks to the following individuals at Taiwan Association of Family Caregivers who provided expertise, answered questions and participated in the review of this chapter:

- Ching-Ning Chen, Executive Director
- Hsiao-Chan Chang, Deputy Office Manager
- Chia-Ning Kuo, Policy Lead
- Tsuann Kuo, President of the Board
- Chi-Yin Yeh, Office Manager

Thanks to the following organizations who provided photographs:

- Ministry of Health and Welfare, R.O.C. (Taiwan)
- Taiwan Association of Family Caregivers
- Taiwan Catholic Foundation of Alzheimer's Disease and Related Dementia
- Global Views Monthly

SOURCES:

- Ministry of Health and Welfare, R.O.C. (Taiwan) Taiwan Health and Welfare. [Website](#)
- National Statistics, the R.O.C.Taiwan. [Latest Indicators](#).

In the United Kingdom, the term 'carer' is most frequently used. Carers are people who look after family members, friends or others because of long-term physical or mental ill health or disability, or care needs related to old age.



POPULATION DENSITY..... 281 per sq km*
POPULATION URBAN 83.2.%*
MEDIAN AGE 40.5 years*
TOTAL DEPENDENCY RATIO* 57.1 **

* [Worldometer](#)

** [Wikipedia](#)

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64).
The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents



UNITED KINGDOM

13,600,000¹ CARERS
Over the age of 18 years

20%² OF POPULATION

¹ Estimate based on: Carers UK. (2020) Carers Week 2020 Research Report

² UK 2020 Population: 67,969,891 ([Worldometer](#))



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



UNITED KINGDOM

LEGISLATION

In England, unpaid carers are legally defined as people who look after family members, friends or others because of long-term physical or mental ill health or disability, or care needs related to old age. [The Care Act 2014](#) introduced new legal rights for carers, including the right to an assessment and access to support. In the legislation, they have parity of esteem with people needing care. [LEARN MORE](#)

Legislation defines young carers in England as being under 18 years of age and providing support to someone in need of care because of disability or illness. [LEARN MORE](#)

There is specific legislation for carers' rights on well-being and social care in Wales ([Social Services and Well-being Act, 2014](#)), Scotland ([Carers Act, 2016](#)) and Northern Ireland ([Carers and Direct Payments Act, 2002](#)).

RECOGNITION

[Carers Week](#) is a UK-wide annual campaign to recognize family/friend caregivers. The campaign is coordinated by [Carers UK](#) and takes place the second week of June. It has wide support from government ministers, often including the prime minister, department staff and parliamentarians.

Developed by Carers UK for Carers Week, [Carer Friendly Communities](#) provides strategies for community-based support for carers. A Carer Friendly Community is a place where carers feel supported to look after their family or friends and are recognised as individuals with needs of their own.

[LEARN HOW EAST SUSSEX IS CREATING A CARER FRIENDLY COUNTY.](#)

[The Carers Action Plan 2018 to 2020](#) sets out a cross-government programme of work in England on devolved matters (i.e., health and social care) and in Great Britain and the UK (i.e., tax is UK wide) on reserved matters (i.e., employment law and benefits). The Plan builds on the [National Carers Strategy](#) to support carers with 64 actions across five priorities, one of which is the support of young carers.



Through the National Health Service (NHS) in England, the [Quality Marker Scheme](#) offers a series of practical ideas that have been developed in partnership with carers, primary care teams and other key stakeholders. Collectively, these provide a framework for improving how local doctors (general practitioners) can better identify and support carers of all ages. The framework provides a range of practical actions grouped into themes and focusses on key areas where the support offered to carers by general practice could be improved. The framework contributes to the evidence of good practice for the regulator, [Care Quality Commission](#), which rates the quality of care.



CARER RECOGNITION (CONT.)



UNITED KINGDOM

RECOGNISING YOUNG CARERS

In June 2020, the BBC highlighted the challenges of young carers. Vignettes described the role of young carers in doing household jobs, such as cooking and cleaning, because their parent or guardian was not able to do it themselves. [LEARN MORE](#)

[The Children's Society](#) runs services for young carers and holds a Young Carers Festival every year. The biggest gathering of young carers in the world, this event allows them to have fun and make new friends, while also serving as a platform for them to be heard and influence change. [LEARN MORE](#)

[Young Carers Awareness Day](#), coordinated by Carers Trust, raises awareness of the challenges faced by young carers and campaigns for greater support for them. After consultation with young carers, starting in 2021 the day will be referred to as Young Carers Action Day.

The [Carers Action Plan Ministerial Oversight Group](#) in England has committed to exploring the potential for:

- establishing a national scheme for young carers to help them gain recognition in the community;
- providing access to discounts that will enable them to better participate in leisure activities with their peers; and
- holding a young carers parliament day to raise the profile of young carers among parliamentarians.

In Northern Ireland, [Northern Ireland Regional Young Carers](#) supports carers aged 8–18.

In 2019, the Welsh government awarded funds to [Children in Wales \(Platn ung Nghymru\)](#) to support young carers to exercise their rights. Once a year, a group of young carers from the Network meets with Welsh ministers to present to the government the experiences and views of young carers in Wales. [LEARN MORE](#)



OPPORTUNITIES

Carers want to be acknowledged and treated equally. With the increasing numbers of carers, there is an opportunity to maintain awareness campaigns and adapt legislation so that carers are identified, and their health and well-being are promoted by health bodies.

[LEARN MORE ABOUT THE CARERS UK'S MANIFESTO FOR CARERS.](#)





FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



UNITED KINGDOM

CARER'S ALLOWANCE

The [Carer's Allowance](#) is the main benefit for unpaid carers, aged 16 and over, in the UK. The unpaid carer must meet specific criteria to qualify and may not be in full-time study or able to receive another similar income replacement benefit in addition to the Carer's Allowance.



In Scotland, the [Carer's Allowance Supplement](#) was introduced in 2018. The allowance is only payable to carers who live in Scotland with payments made every six months.

An additional payment, called the Premium, Addition or Element, which tops up the Carer's Allowance, is available based on means testing. [LEARN MORE](#)

[Personal Budgets](#) or [Direct Payments](#) can be requested and, if deemed eligible by the local authority, payment is made in a lump sum or a series of payments to enable the direct purchase of services. Carer Personal Health budgets also provide allocated funding for a carer. Both types of funding are often relatively small.

PENSION CREDITS

If carers receive a Carer's Allowance, they automatically receive credits toward their State Pension. If they do not receive a Carer's Allowance, they may apply for [Carer's Credit](#) toward their State Pension if they provide over 20 hours of care per week and meet the entitlement criteria.

Unpaid carers who are state pension age may receive a State Pension, but they cannot receive the full amount of both the Carer's Allowance and the State Pension at the same time. This is because they are both classed as the same type of benefit—an income replacement benefit. [LEARN MORE](#)

YOUNG CARER GRANT

The government of Scotland established a [Young Carer Grant](#), a yearly payment available to 16–18-year-old carers to support them to do the things that are the norm for their non-caring peers, such as participating in education, training and personal development.

DISABILITY BENEFITS

A number of different benefits are available to help the disabled person with the additional costs of disability. These include the Disability Living Allowance for disabled children, the Personal Independent Payment for working age disabled people and the Attendance Allowance for people of state pension age.

OPPORTUNITIES



Governments must ensure that carers and their families do not suffer financial hardship as a result of caring. An estimated 1.2 million carers are living in poverty. Two-thirds of carers providing substantial care pay toward the cost of care for their loved one, and over half (53%) are unable to save for their future or for retirement ([State of Caring 2019, Carers UK](#)).



WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



UNITED KINGDOM

WORK & CARE

Carers are protected under the [Equality Act 2010](#) from discrimination by association with someone with a disability. This applies to the workplace as well as across service provision. Unpaid carers have a legal right to request flexible working and are legally entitled to a limited amount of unpaid time off for emergencies involving dependents. However, paid leave or longer or planned time off is subject to negotiation between employers and employees, rather than a guaranteed right. [LEARN MORE](#)

As part of the [Carers Action Plan 2018–2020](#), the government has committed funds to support 'returners', people who have taken time out of employment for caring responsibilities and want to return to paid work.

[Employers for Carers](#), key purpose is to ensure that employers have the support to retain and manage employees with caring responsibilities. Launched in 2009 as an employers' membership forum, Employers for Carers now has 260 employers covering three million employees across the public, private and voluntary sectors. In addition to advocacy and awareness activities, Carers for Employers promotes and supports a framework for a positive and inclusive workplace for all staff, including carers.

The [Wales Hub of Employers for Carers](#) has been established to support organisations based in Wales to be more carer-friendly.

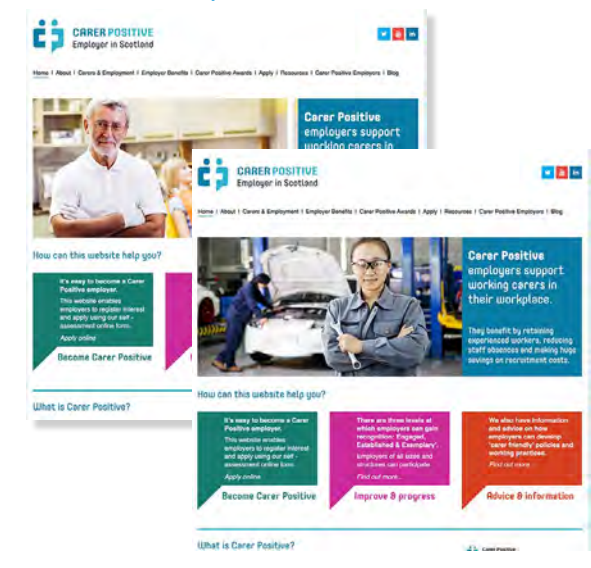
The [Carer Confident](#) benchmarking scheme, supported by the Department for Health and Social Care in England, encourages workplaces to have policies in place and a culture that enables carers to stay in employment. There are three levels of employer ranking: Active, Accomplished and Ambassador.

The online resource [Flexible Jobs Hub](#) reduces barriers for carers to access the flexible roles they report they need. The Hub offers job searching by flexibility as well as advice on finding a suitable job and case studies featuring individuals' experiences.



[Carer Positive](#) is a Scottish government-funded initiative operated by Carers Scotland. The aim of this initiative is to recognise employers who offer the best support to carers. In addition to recognising employers, Carers Positive provides resources to help employers develop the package of support best suited to their particular circumstances. It offers examples of the types of measures employers can take to provide a supportive working environment for carers in their workforce.

[LEARN MORE](#)





WORK & EDUCATION (CONT)



UNITED KINGDOM

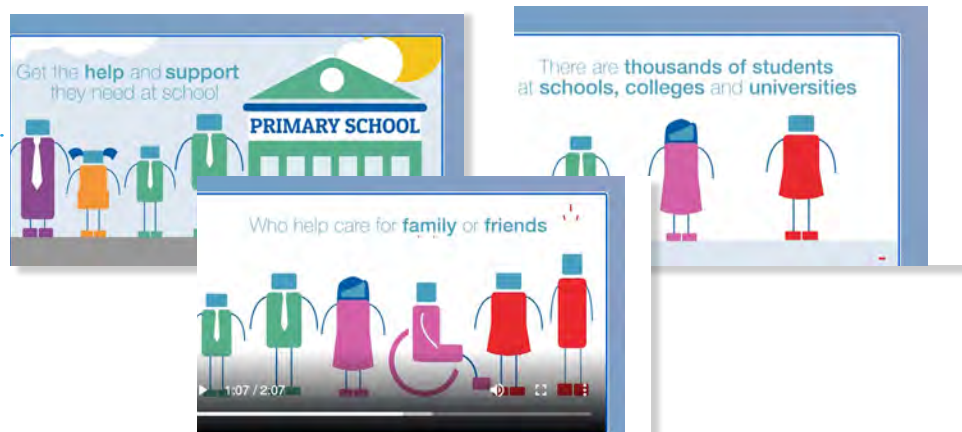
EDUCATION & CARE

Many universities and colleges have initiatives or support programmes in place to help students with care responsibilities. Since 2018, the standard university application form allows a young adult carer to identify themselves if they wish to. The University and Colleges Admission Services (UCAS) provides helpful information about how to manage caring responsibilities along with the requirements for a course. [LEARN MORE](#)

The [Education and Libraries \(Northern Ireland\) Order 2003](#) compels teachers to be responsible for safeguarding and promoting the welfare of all their students. As a result, they are responsible for identifying and supporting young carers.

Carers Trust Wales provides resources to support the identification, attainment and well-being of students with caring responsibilities. [LEARN MORE](#)

[Young Carer Passport for Schools & Universities](#) is an effective way of supporting young carers. See what a difference a passport can make.



The [Government of Scotland](#) acknowledges young carers and has a [Young Carers Support Package](#) as part of their [Young Scot](#) card, which offers opportunities for education and leisure for those aged between 11 and 18 years. [LEARN MORE](#)

OPPORTUNITIES



WORK: Caring and employment has become an increasingly important issue as employers recognise a growing number of their employees are carers and that there are business benefits to be gained to retaining carers in the workplace. COVID-19 has brought carers' needs into sharp focus and has helped employers see the effectiveness of flexible work solutions. This experience should be leveraged to better support carers.

EDUCATION: There is increasing recognition that young carers and young adult carers need more support. Opportunities should be provided to identify young carers more systematically at schools and through local authorities and health care providers.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.

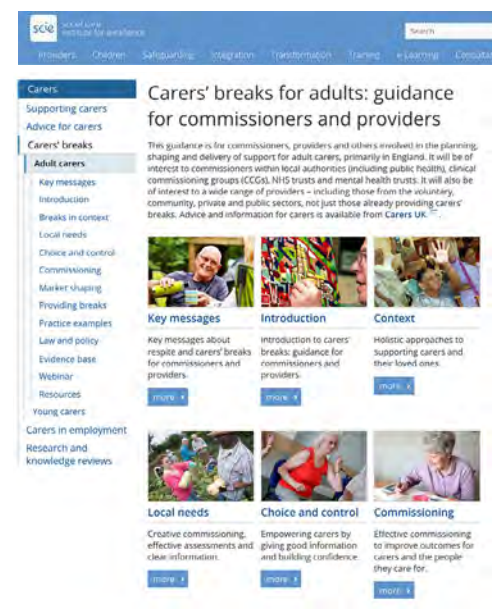


UNITED KINGDOM

BREAKS & RESPITE CARE

Various forms of breaks are provided directly or commissioned through local authorities. They include day care, homecare from a paid carer, a short stay in a care home, getting friends and family to help, respite holidays and sitting services, after an assessment of the unpaid carer or the care recipient is completed. The National Health Service also provides support for breaks and respite when someone is entitled to NHS Continuing Healthcare and has high health needs. [LEARN MORE](#)

[Best Practice Guidance](#) for Local Authorities, Clinical Commissioning Groups and other commissioners have been developed. The guides are for those involved in the planning, shaping and delivery of support for adult, young and young adult carers. The goal is to develop positive respite services through understanding the diversity of carer needs, enabling co-design with carers and facilitating partnerships with stakeholders. The guides are available for both adults and young carers. [LEARN MORE](#)



EMOTIONAL & SOCIAL

As part of the commitment to tackling loneliness and social isolation, the government has established the [Building Connections Fund](#), which is investing in a number of projects that will increase support for carers.

Digital resources and virtual applications are increasingly being used to support and connect carers. The weekly online programme [Care for a Cuppa](#) enables carers to meet and chat through Zoom; [Share and Learn](#) is a virtual wellness event held during Carers Week; and [Me Time](#) offers online sessions focussed on carer health and wellness funded through the Welsh government. Session topics are completely open or thematic, guided by what carers most want to hear or learn about. As well as being quite social, they provide a forum for mutual support and, in some formats, learning. In Wales, some sessions are conducted in Welsh as well in English.

Social prescribing is an expanding concept throughout England to help people with social, emotional or practical needs. General practitioners are able to refer to a link worker to access community-based support, as opposed to medication, to improve the health and well-being of their patients through activities such as art classes, physical activity and carers' support groups. [LEARN MORE](#)





HEALTH & WELL-BEING (CONT)



UNITED KINGDOM

The [Northern Ireland Regional Young Carers](#) provides direct supports to carers aged 8–18, including needs assessment, advice and guidance, individual and group support, help to access specialist services and universal services such as leisure and youth services.

[Young Minds](#), a leading UK charity committed to improving the emotional well-being and mental health of children and young people, provides 24/7 text support for young carers, recognising that young carers miss an average of 48 days of school and 68% have been bullied.

Carers UK

Offers support to carers across the UK.
Runs an online forum for carers to get advice and share their experiences and feelings.
Phone: 0808 808 7777
Email: advice@carersuk.org
Opening times: 9am - 6pm, Monday - Friday

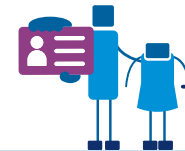
Young Minds Crisis Messenger

Provides free, 24/7 text support for young people across the UK experiencing a mental health crisis.
All texts are answered by trained volunteers, with support from experienced clinical supervisors.
Texts are free from EE, O2, Vodafone, 3, Virgin Mobile, BT Mobile, GiffGaff, Tesco Mobile and Telecom Plus.
Texts can be anonymous, but if the volunteer believes you are at immediate risk of harm, they may share your details with people who can provide support.
Text: YM to 85258
Opening times: 24/7

Youth Access

Provides information about local counselling and advice services for young people aged 12-25.
You can find local services on their website.

Carer Passport



[Carer passport](#) offers a variety of different mechanisms to aid identification and support for carers. This includes a Carers Passport in a hospital, in a community setting or at work. The community-based Carer Passport often doubles up as a form of identification for carers, and sometimes functions as an emergency card. It also often offers discounts to local businesses or activities. The Working Carers Passport is the most popular and relatively quick to implement. This provides a template for employees and employers to the carers' needs and sets out the employer's response. Carer Passports are supported by the Department for Health and Social Care in England and are part of the Carers Action Plan 2018–2020. The Carer Passport was selected as an [Innovative Carer Practice](#) by IACO. [LEARN MORE](#)



OPPORTUNITIES



There is an opportunity for health systems across the UK to do more for carers' health and well-being through expanded carer rights and increased recognition and identification of carers. This is an opportunity for the future that should help health systems manage as populations age, whilst also maintaining carers' health and well-being. Well-being is an increasingly popular concept.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



UNITED KINGDOM

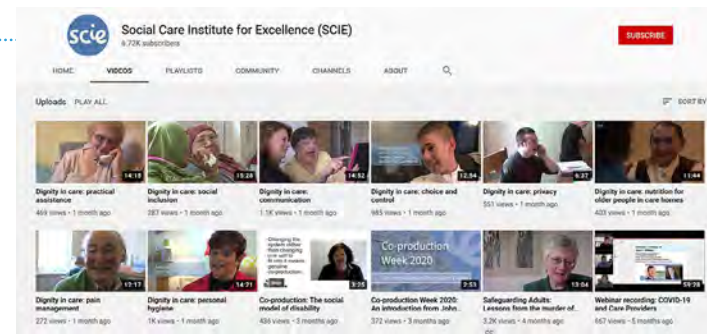
Local authorities have a duty to provide information to carers about their rights and local services available. They may also provide some training. [LEARN MORE](#)

[Upfront guide to caring](#) is a digital personalised information plan that provides carers with links to relevant information. After asking carers to answer a few simple questions, the program prioritizes and sorts through the vast array of resources and information and produces a plan with suggested resources. This five-minute interactive process eliminates the need for endless scrolling and establishes a plan so carers have the right information to address their needs.

[MyBackUp](#) is a contingency planning tool for carers. Developed in response to the widespread uncertainties experienced during the COVID-19 pandemic, this tool addresses one of the main carer concerns of 'what happens if I can no longer care?'. This online tool poses several questions to the carer to gauge their unique situation and needs. A tailored guide provides information with links to resources for carers to consider in planning for contingencies.

e-Learning for Health Care, a Health Education England Programme in partnership with the NHS, Carers UK and [Agylia Care](#), offers specialized e-learning on topics for carers on dementia, mental health, physical disability, infection protection and end-of-life care. [LEARN MORE](#)

The [Social Care Institute for Excellence](#) has a number of online video resources and provides advice for carers on topics such as caring safely at home, reablement and dementia.



Carers UK provides extensive information, practical supports and e-learning throughout the UK.

[LEARN MORE](#)

OPPORTUNITIES



Carers' need for information remains a key priority, as does knowledge of systems and how they work, the condition, how to care safely and well, and how to look after their well-being. Digital information opens up a wealth of accessibility possibilities supporting face-to-face information.

INNOVATIVE CARER PRACTICES



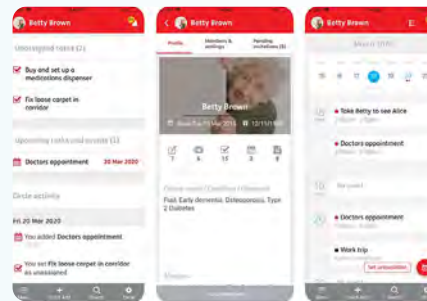
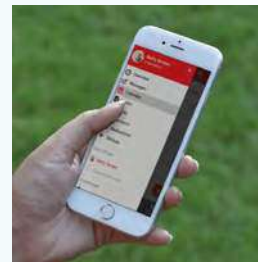
Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

INNOVATION IN UNITED KINGDOM

[Jointly app](#), developed by Carers UK, is an innovative mobile and online app that is designed by carers for carers. This app helps with care coordination, maintains medication lists, uses a diary to document and coordinate appointments, and includes a function to assign tasks to individuals along with key information. The expandable app enables carers to create several different care circles if they wish.

Key features include:

- simple, intuitive group communication with everyone in the carers' 'Jointly circle';
- management of notes, creation of health logs and storage of bills and other information;
- organisation and response to tasks with options to assign the task to any member of the Jointly circle and monitor its status;
- connections with members inside and outside the Jointly circle with the creation of events and invitations;
- easy access and storage of useful information about the care recipient;
- medication management to keep track of current and past medication of the care recipient; and
- resources for useful contacts so carers can access contact details anytime, anywhere.



'Looking after someone can be so complicated. Jointly helps me stay on top of things and share information easily with everyone involved in my son's care'.



Carers UK (established in the early 1965) supports carers and provides information and advice about caring, influences policy through research based on carers' real-life experiences, and campaigns to make life better for carers.

Special thanks to Emily Holzhausen, OBE, Director of Policy and Public Affairs, Carers UK, who provided expertise, answered questions and participated in the review of this chapter.

SOURCES:

- House of Commons Library. (2017). [Carers Briefing Paper](#).
- International Alliance of Carer Organizations. [Principles for Carers](#).
- [The Ministerial Advisory Group for Carers – 2018/19 Annual Plan](#).
- Department of Health & Social Care. (2019). [Carers Action Plan 2018-2020, Supporting carers today—One-year on progress review](#).

In the United States, the term ‘family caregiver’ is most frequently used. Family caregivers are not exclusively related to the person to whom they are providing; they include anyone who provides unpaid care or support to a family member or friend.



POPULATION DENSITY..... 36 per sq km*
POPULATION URBAN 82.8%*
MEDIAN AGE 38.3 years*
TOTAL DEPENDENCY RATIO..... 53.9**

* Worldometer

** Wikipedia

Ratio of combined youth (ages 0–14) and elderly (ages 65+) populations per 100 people of working age (ages 15–64). The higher the dependency ratio, the more the working age population has to contribute to sustain its dependents.



UNITED STATES

53,000,000¹ CARERS

Over the age of 18 years

3,400,000¹ CARERS

Under the age of 18 years

21.3%¹ OF POPULATION

¹ National Alliance for Caregiving & AARP Public Policy Institute (2020)



CARER RECOGNITION

Policies and programmes to increase recognition of the central role carers play in the well-being of the person they are caring for, in community capacity, in society and in economic prosperity.



USA

LEGISLATION

The [Recognize, Assist, Include, Support and Engage \(RAISE\) Family Caregivers Act of 2018](#) requires the US Department of Health and Human Services to develop and maintain a strategy to recognise and support adult family caregivers. This legislation defines the family caregiver as ‘an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation’. The strategy will identify actions that communities, providers, the government and others are taking, and may take, to recognise and support family caregivers.



To support the development and execution of the strategy, the RAISE Act also directed the establishment of the [Family Caregiving Advisory Council](#). The Council is charged with supporting the development and execution of a national caregiving strategy with recommendations to support the following actions:

- Promote greater adoption of person- and family-centred care in all health care and long-term service and support settings, with the person and the family caregiver at the centre of care teams.
- Involve care recipients and family caregivers in assessment and service planning (including care transitions and coordination).
- Expand information, education, training supports, referral and care coordination.
- Increase respite options.
- Improve financial security and workplace issues.

The Council must include up to 15 voting members who reflect the diversity of family caregivers and people who receive support. In addition, the council includes non-voting representatives from federal departments and agencies that play a role in these issues. [LEARN MORE](#)

The National Family Caregiver Support programme ([Section 371 of the Older Americans Act of 1965](#), as amended, Title III-E) involves making federal grants to states to assist in the cost of carrying out state programmes to enable agencies on ageing to provide systems of supports for family caregivers.

The [Caregiver Advise, Record, Enable \(CARE\) Act](#) is state legislation that includes three important components to be addressed when a person is admitted to hospital in order to enable a smooth transition between home and hospital. The CARE Act is law in [most states](#), as well as the District of Columbia, Puerto Rico and the US Virgin Islands.

The expectations of the CARE Act are that:

- 1 the family caregiver is identified
- 2 the need for complex care tasks to be completed by the family caregiver is determined
- 3 an anticipated discharge date is provided

The [Supporting Grandparents Raising Grandchildren Act, 2018](#), established an Advisory Council to identify, promote, coordinate and disseminate information, resources and best practices to the public that are available to help grandparents and other older relatives to meet the health, educational, nutritional and other needs of the children in their care, and maintain their own physical and mental health and emotional well-being.

In 2020, the Department of Veterans Affairs launched the expansion of the Program of Comprehensive Assistance for Family Caregivers (PCAFC) to caregivers of eligible veterans of earlier eras. [LEARN MORE](#)

The [Plan to Create a 21st Century Caregiving and Education Workforce](#) is a commitment made by the new 2021 presidential administration. The commitment is to advance a \$775 billion caregiving plan aimed at improving delivery of home- and community-based care, strengthening the caregiving workforce and establishing tax and Social Security credits for unpaid family caregivers, among other initiatives.



CARER RECOGNITION (CONT)

November is [National Family Caregivers Month](#), which serves as a time to recognise and give praise and support to people who dedicate their time, often unpaid, caring for a family member in need. President Clinton signed the first NFC Month Presidential Proclamation in 1997. Every president since has followed suit by issuing an annual proclamation recognising and honouring family caregivers each November. The national observance is led by the [Caregiver Action Network](#) along with many other national organisations. [LEARN MORE](#)



YOUNG CARERS

The [Caregiving Youth Institute](#) is a division of the [American Association of Caregiving Youth](#). The CYI was established in direct response to the growing number of caregiving youth who are unrecognised, invisible and falling through the system cracks in health care, education and the community. The CYI seeks to further increase the level of awareness of the multi-system needs of caregiving youth along with providing solutions for their support through the multiple initiatives of connection, advocacy, research and education (C.A.R.E.).

An estimated 20% of children caregivers in the United States are non-White, compared to 9% of children caregivers who are White.

[LEARN MORE](#)



The number of caregivers in the United States is only an estimate as there is no national agreed-on census figure.



USA

OPPORTUNITIES



Adopt a unified caregiving strategy that aligns with global and national efforts to improve the lives of family caregivers with services and supports that aid caregiving across the lifespan (from infancy to older adulthood).

Promote a six step strategic process to guide states that have not yet created a strategy to support caregivers across the lifespan, including formal recognition; needs assessment and supports; sharing best practices; person-centred policies; stakeholder engagement; and evaluation. [LEARN MORE](#)



Increase awareness and support of young caregivers across the United States.



FINANCIAL SUPPORT

Measures to support carers' financial security and alleviate the pressure on personal finances from caring.



USA

FINANCIAL ASSISTANCE

Family caregivers can receive financial assistance, income or tax breaks to reduce the burden of the cost of caregiving. These options are embedded in various government programmes and tax incentives if certain qualifying criteria are met. This support is extremely limited and is needs-tested. There are long waiting lists to receive the support, and it is not available in all states.

Medicaid Support for Caregivers is offered at the discretion of states. A variety of innovative support initiatives have been, and continue to be, tested in a number of states. In some cases, care recipients can be reimbursed to manage their own home care, programmes that are referred to as Consumer-Directed Care, Participant-Directed Services, In-Home Supportive Services, or Cash and Counseling. These programmes can, in some states, include hiring a family member to provide care. [LEARN MORE.](#)



Medicaid is a federal programme that provides health coverage to low-income people. It is one of the largest payers for health care in the United States.

The [US Department of Veteran Affairs](#) offers four plans for financial support:

1. [Veteran Directed Care](#) – monthly funding that may be used to select and reimburse a caregiver.
2. [Aid and Attendance benefits](#) – benefits that supplement a military pension to help cover the cost of a caregiver, who may be a family member.
3. [Housebound benefits](#) – monthly pension supplement for those on a military pension and who are substantially confined to the home. This benefit and A&A cannot be received at the same time.
4. [Program of Comprehensive Assistance](#) – monthly stipend to family caregivers for veterans whose needs are the result of a traumatic injury sustained in the line of duty on or after September 11, 2001. This programme was expanded to combat veterans of other conflicts in the VA Mission Act of 2018.

Unpaid family caregivers who are [representative payees](#) (e.g., financial trustees of fiduciaries for the caregiver) can apply for Social Security disability benefits for the care recipient. Two types of disability benefits are paid to the care recipient, who may use the funds to support their caregiver:

- [Supplemental Security Income](#) – a monthly cash benefit from the federal government to meet basic needs for food, clothing and shelter for low-income older adults and people with disabilities.
- [Social Security Disability](#) – a monthly cash benefit from the federal government for people who are unable to work for a year or more because of a disability.

Some private long-term care insurance plans cover some costs for home health care and personal care services and may extend that coverage to paying spouses or other family caregivers living in the home. The availability is extremely limited and the cost prohibitive for many.





FINANCIAL SUPPORT (CONT)



USA

TAX BENEFITS

The Family Tax Credit or [Credit for Other Dependents](#) allows family caregivers who pay at least 50% of living expenses to claim a tax credit of \$500 for dependents who rely upon them exclusively for care.

[Medical Expense Deduction](#) –

unreimbursed medical costs can be deducted if the qualified medical expenses of everyone claimed totals more than 10% of the adjusted gross income for the year and if the total itemized deductions are more than the standard deduction.



[Child and Dependent Care Credit](#) – family caregivers can claim a portion of up to \$3,000 in caregiving costs for one person and up to \$6,000 for two or more qualifying people (e.g., child under the age of 13 and spouse physically or mentally incapable of self-care), provided the expenses are for the care-recipient's well-being and protection. Other deductible dependent care benefits must be subtracted from this claim.

Flexible spending accounts (FSAs) and health savings accounts (HSAs) – permit pre-tax earnings to be deposited in a medical savings plan to be used when needed to pay out-of-pocket health care costs for oneself and/or dependents. If using an FSA or HSA, a tax deduction cannot be made for that bill as a medical expense. [LEARN MORE](#)



IACO believe that to ensure sustainable long-term care systems, the unique needs and contributions of carers must be considered in health and social policies and programming.

OPPORTUNITIES



Develop adequate supports to defray the out-of-pocket costs of care incurred by family caregivers, averaging \$7,000 per year.

Protect and maintain social security retirement benefits when caregivers voluntarily leave the workforce to assume full-time caregiver responsibilities.





WORK & EDUCATION

Practices to create supportive workplaces and educational environments so carers have equal opportunities to remain in and return to work/school.



USA

WORK & CARE

The United States lacks a national mandate on comprehensive paid family leave.

The Civil Rights Act of 1964 protects workers against discrimination. In 2007, the US Equal Employment Opportunity Commission (EEOC) issued guidance, [Employer Best Practices for Workers with Caregiving Responsibilities](#), for employer best practices specific to caregiving. The AARP Fact Sheet, [Protecting Family Caregivers from Employment Discrimination](#), summarises the EEOC guidance.

Federal legislation introduced in June 2020, the [Protecting Family Caregivers from Discrimination Act](#), would prohibit employers from firing, demoting, mistreating, refusing to hire, or taking other adverse employment action against workers who are caregivers for their loved ones. [LEARN MORE](#)



The federal [Family and Medical Leave Act](#) (FMLA) guarantees eligible workers unpaid job-protected leave for specified caregiving reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave. The intent is that workers should not have to choose between employment and caregiving. Eligible employees can take a 12-week leave in a 12-month period to care for a newborn or to care for the employee's spouse, child or parent who has a serious health condition. Twenty-six weeks is permitted for military caregiver leave. [LEARN MORE](#)

Over 30 states have enacted multiple bills related to paid and unpaid family and medical leave. [LEARN MORE](#)

Some employers provide workplace benefits for caregivers, such as paid family leave and paid sick days.

In Hawaii, the [Kupuna Caregivers Program](#) (KCGP) is a pilot programme launched in 2018 that is intended for employed Hawaiian residents who are also unpaid primary caregivers of a senior relative. This programme helps ease the financial burden of providing care for a loved one, while allowing the caregiver to continue their employment outside of the home. This programme is also called the Kupuna Caregiver Law.

EDUCATION & CARE

The [American Association of Caregiving Youth](#) (AACY) established the first US [Caregiving Youth Project](#) (CYP) in 2006. The programme supports young caregivers to maintain their education and graduate from high school.

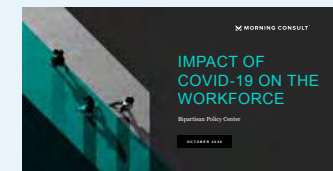


OPPORTUNITIES



Increase employers' understanding of the benefits of programmes that support greater awareness of and responsiveness to employees when they are serving as family caregivers.

[LEARN MORE](#)



Learn from the experience of COVID-19 that policies supporting caregivers (e.g., paid family leave) are needed so employees can better manage family responsibilities while staying connected to the workforce.

[LEARN MORE](#)

Develop a strategy to support young caregivers to pursue their education.



HEALTH & WELL-BEING

Supports to uphold carers' physical and mental health, facilitate social connections and enable carers to pursue interests outside of their caring responsibilities.



USA

RESPIRE CARE

Respite is available through the [National Family Caregiver Support Program](#) (NFCSP), which provides grants to states (see the Information & Knowledge section). In fiscal year 2014, respite care services were provided to more than 604,000 caregivers through nearly six million hours of temporary relief from caregiving responsibilities. These services were provided at home or in an adult day care or institutional setting.

The [Lifespan Respite Care Program](#) gives competitive grants to agencies to provide a coordinated system of accessible, community-based respite care services at the state and local levels. The programme is designed for family caregivers of children and adults of all ages with special needs.

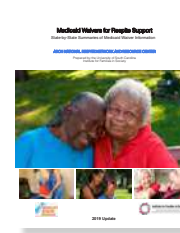
The [Department of Veterans Affairs](#) provides home-based and nursing home respite.

Respite can be included in a health insurance plan for the care recipient. Many home-and community-based services also offer respite through health care providers.

[Medicare](#) may include short-term respite care for up to five days as an inpatient. This is arranged by the hospice provider and can be offered more than once on an occasional basis. [Medicare Advantage plans](#) may have a respite care benefit available to caregivers to give them a break from supporting the activities of daily living. Under [the Special Supplemental Benefits for the Chronically Ill program](#), plan benefits may also include access to companion care, marital counselling, family counselling, paid caregivers of children, or programmes that can help address isolation and improve emotional and/or cognitive function. Under Traditional Medicare, some CPT (or 'billing') codes may offer a provider reimbursement for services provided to a family caregiver.

Medicaid has made available several state options that pay for home- and community-based services, including respite and/or personal care services for consumers, which provide an opportunity for family caregivers to receive a break from their duties. [LEARN](#)

[MORE](#)



[State Respite Coalitions](#) are grassroots membership organisations composed of state and local, public and private organisations. They represent people of all ages with disabilities or chronic conditions; family caregivers; community and faith-based organisations; and respite, social service and health care providers. Their activities are focused on advocacy, networking and public education. Some coalitions also provide training and respite vouchers. They may be run by volunteers or paid staff.

Adult day programmes provide support and respite for family caregivers. There are more than 4,000 adult day programmes providing care to over 150,000 adults in the United States.

[LEARN MORE](#)



IACO is building awareness of the role and impact of carers on specific patient populations. [LEARN MORE](#)





HEALTH & WELL-BEING (CONT)



USA

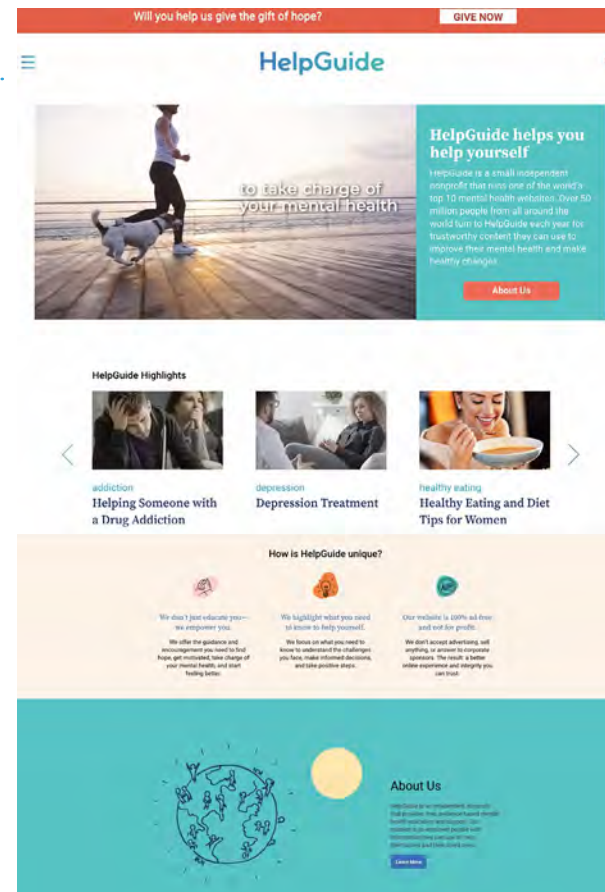
EMOTIONAL & SOCIAL

The US Department of Health and Human Services provides information about caregiver stress and directs caregivers to resources, including [HelpGuide](#). HelpGuide is an independent nonprofit that runs one of the world's top 10 mental health websites.

[AgingCare](#) and [Family Care Alliance](#) are other examples of sites that offer caregivers resources, opportunities for online chat and counselling services.

The Caregiver Action Network provides a free Caregiver Help desk (phone, email and chat) to provide supports and information for caregivers. [LEARN MORE](#)

[Community Care Corps](#) is a national programme that fosters innovative models in which local volunteers help family caregivers, older adults or persons with disabilities with non-medical care in their own homes in order to maintain independence. The goal is to supplement the formal care system by increasing the number of volunteer programmes available at the local level to provide non-medical care to older adults, persons with disabilities and their caregivers. Ultimately, the intent is to find local models that work well so a national volunteer corps can be developed.



OPPORTUNITIES



A unified strategy for establishing caregiver support infrastructure is needed to coordinate efforts and to support the caregiving role across the nation and the lifespan. From [Momentum to Movement](#) advances the establishment of such an infrastructure by presenting a strategic process intended to align the work of state caregiving advocates with multi-jurisdictional policy priorities in key person-centred domain areas.



INFORMATION & KNOWLEDGE

Resources to empower carers that are appropriate to their needs and stage of their journey.



USA

The [National Family Caregiver Support Program](#) (NFCSP) provides grants to states and territories, based on their share of population aged 70 plus, to fund various family caregiver supports so older adults can remain in their homes as long as possible.

The services include:

information to caregivers about available services

assistance to caregivers in gaining access to the services

individual counselling, organisation of support groups and caregiver training

respite care

supplemental services, on a limited basis

[Caregiver Action Network Help Desk](#) offers free support to family caregivers across the country. It is staffed by caregiving experts who can help caregivers find the information they need to navigate their caregiving challenges and support them on their caregiving journey.

[Help for Cancer Caregivers](#) provides information, education and support to help cancer caregivers care for themselves and their family members, such as creating a Personal Care Guide based on caregivers' current sources of strain.

[Rare Caregivers](#) is a comprehensive online guide that addresses the distinct needs of family caregivers of loved ones with rare diseases.

The [Alzheimer's Association](#) provides information and a series of tips for caregivers to learn what to expect and how to prepare based on the different stages of the disease and the family's situation. A live chat with a dementia expert is also available.

The federal government provides a web-based resource of [caregiver resources and supports](#) at the federal, state and local levels.

The [VA Caregiver Support Program](#) and the [National Family Caregiver Support Program](#) both offer training and educational resources.

Unpaid family caregivers have access to training and information through the [Family Caregiver Alliance](#), [AARP](#), the [National Alliance for Caregiving](#) and the [Caregiver Action Network](#).



OPPORTUNITIES



States should ensure family caregivers are prepared to safely perform care coordination and any necessary medical/nursing tasks by providing easily accessible information, education and training that is tailored to their caregiving situations and delivered in culturally competent and evidence-informed ways. [LEARN MORE](#)

INNOVATIVE CARER PRACTICES

Innovative Carer Practices are evidence-informed policies and practices that address carers' needs through integrated health and social care. By identifying and sharing Innovative Carer Practices, IACO facilitates the awareness and spread of leading practices around the world. [LEARN MORE](#)

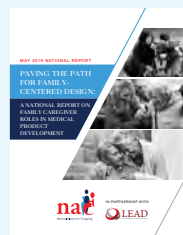
INNOVATION IN USA

Family Caregiver Roles in Medical Product Development

[Paving the Path for Family-Centered Design:](#)

[A National Report on Family Caregiver Roles in Medical Product Development](#),

released in 2019, addresses how to incorporate the critical knowledge of caregivers in developing pharmaceutical products, biologic therapies, diagnostics and medical devices. It is led by the National Alliance for Caregiver (NAC), in partnership with the [Leaders Engaged on Alzheimer's Disease \(LEAD\) Coalition](#), to capture caregivers' lived experiences and perspectives from more than 40 stakeholder groups working in medical product development.



The initiative provides recommendations for leveraging caregivers' pivotal insights into what drugs and devices are needed, what therapeutic benefits matter and how much, what degree of risk or potential harms are tolerable, how clinical research should be conducted, and how safety and efficacy should be measured.



Embracing Carers™ is a global initiative led by Merck KGaA, Darmstadt, Germany, operating as EMD Serono, EMD Millipore, and EMD Performance Materials in the United States and Canada. This collaboration among leading caregiver organisations around the world is designed to increase awareness, discussion and action about the often-overlooked needs of caregivers. They created the [Carer Well-Being Index](#) to determine the current and residual impacts of COVID-19 on unpaid caregivers, including its impact on their economic, physical and psychological well-being.



The **National Alliance for Caregiving (NAC)** (founded in 1996) envisions a society that values, supports and empowers family caregivers to thrive at home, work and life. NAC's mission is to build partnerships in research, advocacy and innovation to make life better for family caregivers. NAC's work is guided by an authentic and passionate commitment to family caregivers that is human-centred, data-driven, collaborative and inclusive.



Caregiver Action Network (CAN), formerly the National Family Caregivers Association (founded in 1993), is the nation's leading

family caregiver organisation working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease or the frailties of old age. CAN is a non-profit organisation providing education, peer support and resources to family caregivers across the country, free of charge.

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