



# **ACKNOWLEDGING AND AIDING CARERS**

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## **A GUIDE TO SUPPORTING CARERS IN YOUR NATION**

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## Acknowledgements

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## October 2017

Dear Colleagues:

The International Alliance of Carer Organizations (IACO) is pleased to present the **Carer Toolkit**. It was developed with generous support from Merck KGaA (Darmstadt, Germany) to whom we are most grateful.

IACO was incorporated in 2012 and currently has a membership of 15 national carer organizations throughout the globe. It was formed to address issues of international family caring and to promote public awareness of the family caregivers on a global scale. In many communities, it is the unpaid friend, neighbour, or relative (family carer) who supports the health and long-term care systems of that region or country.

The goals of IACO are to:

- » Engage members to share and increase knowledge, expertise and experience,
- » Act as a resource for carer organizations globally,
- » Facilitate international advocacy to advance programs, policies and legislation that support carers, and
- » Increase awareness of the role and value of the Alliance.

We developed the **Carer Toolkit** to guide nations with little or no carer infrastructure. It was designed to identify the methods you can implement to form a national carer organization and to suggest some of the areas that you might want to focus on. We recognize that each nation knows best the needs of its citizens, and that you may want to tailor the suggestions in this toolkit to your nation.

We view this document as a beginning, and plan to update it online with more examples of how our members are addressing different carer issues. Expanded versions of this document will be available on our website, which is: [www.internationalcarers.org](http://www.internationalcarers.org)

In the interim, should you have any questions or require additional information, please do not hesitate to contact me at [rickgreene@caregiving.org](mailto:rickgreene@caregiving.org)



**Rick Greene, MSW**

Executive Advisor





## Lexicon of Carer Terminology

This document serves as a reference to terms related to caring or caregiving.<sup>1</sup>

**Activities of Daily Living (ADLs):** Basic personal activities which include bathing, eating, dressing, mobility, transferring from bed to chair, and using the toilet. ADLs are used to measure how much a person may require assistance in performing any or all of these activities.

**Adult Day Care:** A daytime community-based program for adults with disabilities that provides a variety of health, social, and related support services in a protective setting.

**Care Plan (Also called Service Plan or Treatment Plan):** Written document which outlines the types and frequency of the long-term care services that an individual receives. It may include treatment or personal goals for him or her for a specified time period.

**Care/Case Management:** Care/case management assesses clients' needs, creates service plans, and coordinates and monitors services; they may operate privately or may be employed by social service agencies or public programs. Typically, case managers are nurses or social workers who monitor and coordinate treatment rendered to persons with specific diagnoses or requiring high-cost or extensive services. Procedures and processes are used by trained service providers or a designated entity to assist children and families in accessing and coordinating services.

**Developmental Disability (DD):** Also referred to as 'child disability', as it originates before the age of 18. An impairment typically first evident before or during birth or during infancy, childhood or adolescence. Defined relative to age-specific norms. May be genetic or acquired, and usually lasts throughout a person's lifetime. May cause difficulty with language, mobility, learning and independent living. Examples include autism spectrum disorders, cerebral palsy, hearing loss, intellectual disabilities and visual impairment.

**Family Carer/Caregiver:** A person providing unpaid support and assistance with various activities to a family member, friend, or neighbor. May provide emotional or financial support, as well as hands-on help with different tasks. Caregiving may also be done from long distance.

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<sup>1</sup> Not all of these items may be applicable in your country.

**Home and Community-Based Services (HCBS):** Any care or services provided in an individual's place of residence or in a non-institutionalized setting located in the immediate community. HCBS may include home health care, adult day care or day treatment, medical services, or other interventions provided for the purpose of allowing a patient to receive care at home or in their community.

**Home Health Care:** Includes a wide range of health-related services such as assistance with medications, wound care, intravenous (IV) therapy, and help with basic needs such as bathing, dressing, mobility, etc., which are delivered at a person's home. Health services rendered in the home to aging individuals, persons with disabilities, persons with severe and/or terminal illnesses, or convalescent individuals who do not need institutional care. The services may be provided by a visiting nurse association, home health agency, country public health department, hospital, or other organized community group and may be specialized or comprehensive. The most common types of home health care are the following: nursing services; speech, physical, occupational and rehabilitation therapy; homemaker services; and social services.

**Homemaker Services:** In-home help with meal preparation, shopping, light housekeeping, money management, personal hygiene and grooming, and laundry.

**Hospice:** A program which provides palliative and supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient's physician or another community agency. The whole family is considered the unit of care, and care extends through their period of mourning.

**Hospice Care:** Services for the terminally ill provided in the home, a hospital, or a long-term care facility. Includes home health services, volunteer support, grief counseling, and pain management.

**Instrumental Activities of Daily Living (IADLs):** Household/independent living tasks which include using the telephone, taking medications, money management, housework, meal preparation, laundry, and grocery shopping.

**Palliative Care:** A comprehensive approach to treating serious illness that focuses on the physical, psychological, and spiritual needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, controlling pain and the symptoms of pain, and enabling the patient to achieve maximum functional capacity. Respect for the patient's culture, beliefs, and values is an essential component.

**Personal Care (Also called Custodial Care):** Assistance with activities of daily living as well as with self-administration of medications and preparing special diets. Personal services such as bathing and toileting, sometimes expanded to include light housekeeping furnished to an individual who is not an inpatient or a resident of a group home, assisted living facility, or long-term facility such as a hospital, nursing facility, or institution for mental health. Personal care services are those that individuals would typically manage themselves if they did not have a disability.

**Respite Care:** Service in which trained professionals or volunteers come into the home to provide short-term care (from a few hours to a few days) for an individual to allow caregivers some time away from their caregiving role.

**Service Plan (Also called Care Plan or Treatment Plan):** Written document which outlines the types and frequency of the long-term care services that a carer receives. It may include treatment goals for the care recipient and carer for a specified period of time.

**Support Groups:** Groups of people who share a common bond (e.g. caregivers) and come together on a regular basis to share problems and experiences. May be sponsored by carer organizations, social service agencies, senior centers, religious organizations, as well as organizations such as the Alzheimer's Association.

**Transportation Services:** Provides transportation for older adults to services and appointments. May use bus, taxi, volunteer drivers, or van services that can accommodate persons in wheelchairs and other special requirements.

**Treatment Plan (Also called Care Plan or Service Plan):** Written document which outlines the types and frequency of the long-term care services that a carer receives. It may include treatment goals for him or her for a specified time period.

## References:

Adapted from: US Department of Health & Human Services, Office of the Secretary for Planning and Evaluation. *Glossary of Terms*. US Department of Health & Human Services (undated). Found at: [www.aspe.gov/glossary-terms](http://www.aspe.gov/glossary-terms)



# Starting a National Carer Organization

## Introduction

Welcome from the International Alliance of Carer Organizations (IACO). One of our goals is to assist nations with little or no carer infrastructure to develop one appropriate to the needs of their carers.

There are two main ways of starting a carer organization. The first is through a group of carers who come together to start a new national organization. The second is building a coalition of carer groups and other interested parties to form a carer's coalition. Each structure is different and has different ways of operating and being constituted. Carer organizations around the world use both models. Finally, you may wish to begin by developing a carer's coalition in one region of your nation, which over time, can expand into a national carer organization.

## Planning

Planning is essential to the success of building a national carer coalition. Planning activities precede the very first organizational meeting of the coalition and extend throughout the existence of the coalition. Planning helps to rally those initially invited to participate, creates and validates the vision and mission, and serves as a check on progress.

Prior to the formal planning process the following should be taken into consideration:

- » Consider whether you want a formal planning process to be the very first activity of the coalition. You may decide it would be good for the coalition to first work together on a specific achievable project, such as a formal needs assessment project or educational conference.
- » Consider the length of the planning process. State an end date so that those involved are convinced of the reality of an outcome.
- » Consider who will facilitate the planning process. An outside facilitator who is skilled and has a proven record at facilitating may be best.
- » Consider reaching out to national carer organizations in other nations. IACO can assist you with this, and our members will gladly share their experiences in forming their organization.



## Gathering Information

### Needs assessment

A needs assessment is a process to identify the needs of carers and available services in a community so that gaps in services can be identified, and needed services developed or expanded. As you begin conversations about starting a caregiving coalition, one of the first steps should be to gather information, starting with a review of existing demographic information about your nation and existing information available about family caregivers. The information gathering process will help identify gaps in knowledge, and will then ultimately help define the reasons why organizations and individuals should come together now to form a national caregiving organization.

The first stage of information gathering, or a preliminary assessment, should provide you with data for many of the following questions. Not all of this information may be available in your nation. You may want to conduct focus groups of carers and have them identify the challenges they face and the services that would make their lives easier.

### Things to consider

- » What's the estimated number of family carers in your nation?
- » What services or resources are available to the carer? What services are lacking?
- » What is the current level of utilization of these resources and services?
- » Are there carers who are not utilizing services? If so, what is an estimated number? Why are they not using services?
- » Do the existing services address the variety of needs carers have at different points in their caregiving experience?
- » What caregiving tasks are families providing in your country?
- » What are the barriers to access for the caregiver (time, cultural difficulties, son/daughter or spousal responsibility, communication gaps, overwhelmed feelings)?
- » What is the racial/ethnic breakdown of carers in your country?
- » Have any research studies on carers been conducted?

This information can be supplemented with knowledge from those invited to the exploratory meeting by asking them to complete a brief questionnaire to get their views on the unmet needs in the country and, therefore, the need for a national carer organization.

The information gathered in the preliminary assessment may be sufficient to identify the needs of carers. If, however, some of the information is outdated and not adequate to identify the needs of family carers, the coalition may want to undertake a formal needs assessment study as one of its first projects. Local universities are good resources in conducting needs assessments because of their research expertise.

The extent of the needs assessment can vary based on the budget and areas that the coalition has identified as containing the greatest gaps in knowledge. For example, a needs assessment may include some or all of the following:

- » **Survey of carers,**
- » **Survey of service providers,**
- » **Survey of other community groups and organizations with a voice in caregiving issues,**
- » **Survey of patient organizations,**
- » **Focus groups or town hall meetings.**

### Key Stakeholders and Recruitment

Since the focus of the carer organization will ultimately be national, it is important to identify those potential partners to be invited to the initial meeting. Identifying potential key leadership is also important at this point - those individuals who will help in the strategic development of the national coalition (more in the leadership section below). The first step is to identify the key stakeholders that will be invited to be part of the original convener group. These might include:

- » **Family carers,**
- » **Government officials with jurisdiction over carer issues (Health, Labor and Social Services Ministries),**
- » **Leading service provider organizations in your country (insurers, health care organizations),**
- » **Family and patient advocates who have a broad network of contacts,**

- » Leaders in aging services and the disability network,
- » Physician groups and other professional organizations,
- » Nonprofits serving various chronic conditions.

Once the original convening group has been assembled, it is time to develop a list of organizations and/or individuals you wish to invite to join a collaborative effort to address the needs of family carers. Below is a list of the organization types you may want to include.

- » Family carers,
- » Public and private organizations,
- » Voluntary health organizations (Alzheimer's Association, Cancer Society, MS Society),
- » Advocacy organizations and membership groups,
- » Employers,
- » Faith-based organizations and faith communities,
- » Groups representing different cultures within the community,
- » Other coalitions that interface with family caregiving issues,
- » Political leaders and elected officials,
- » Media,
- » Women's groups,
- » Veterans organizations,
- » Legal service providers,
- » Colleges and universities,
- » Hospital and Health Service Organizations,
- » Nontraditional organizations and groups.

## Articulating the Purpose of your Coalition

Coalitions are formed for a variety of reasons, whether it be mandated by law, required to fulfill funding requirements or inspired by family caregivers and their advocates motivated to enhance services and support for family caregivers. That initial catalyst, along with the preliminary assessments of family caregivers in the community and a

planning process that includes the creation of a vision and mission will all help to define the role and purpose of your coalition.

In other words, what will this gathering of expertise contribute toward the support of the family carers? Some possible purposes for a family carer coalition include one or more of the following:

- » **Advocacy** – The coalition becomes a voice with the family carer advocating for changes in the law and regulations. This can include working with local, regional and federal governments to effect change. The coalition may select one particular group of family carers (e.g., carers of older persons or grandparents or other relatives caring for children under the age of 18).
- » **Outreach** – Outreach includes providing information, education and referral services to the public. Because information provided to carers may currently be limited in scope, depending upon the organization providing the information, and because funds for outreach may be limited within organizations, the coalition may gather to improve outreach to the community.
- » **Raising Awareness** – A problem of self-identification exists among family carers. The coalition may help tell the story of the family caregiver to raise awareness of the resources available to caregivers. Awareness building may also take place with employers and others who interact with family carers in their day-to-day lives.
- » **Service Provision** – Coalitions may identify gaps in service delivery in the community.

A key component to success is linking your coalition with complementary organizations in your nation and taking advantage of their resources and their network of members.

## Coalition Scope

The definition of community and an initial idea of the purpose of the coalition can help to define the scope of the coalition. Scope can be defined in several ways.

- » **Geographic** – The scope of the coalition initially will be nation-wide. Over time, you may wish to consider developing affiliate organizations at the regional or local level.
- » **Resource Levels** – The resources available can define the scope of the coalition's work.
- » **Partners/Members** – The partners who join the coalition and who are willing to commit time and resources toward success may also define the scope of the coalition's work.
- » **The scope of the coalition may also change over time.**



## Creation of the National Alliance for Caregiving (NAC) in the United States

In 1993, Gail Hunt, the current CEO of NAC had a for-profit management consulting firm in aging. She was approached by a colleague who had a client--Glaxo Smith Kline (GSK) - which was interested in funding the startup of a coalition of national groups in the area of aging. GSK hired her to find an aging topic that was underserved where organizations were willing to be in a coalition. After several interviews with national groups, she decided that family caregiving was an area that deserved attention.

In 1994, GSK provided a two-year planning grant to the original five organizations—American Society on Aging, National Council on Aging, AARP, the Veterans Administration, and the National Association of Area Agencies on Aging. Ms. Hunt gave up her consulting work and became the Executive Director. The planning grant allowed NAC to create a board of directors and the mission and vision of the Alliance. For example, it was decided to focus NAC on unpaid caregiving by family and friends since the new organization was just starting out and unprepared to take on the labor issues of direct care workers. The decision was also made to include caregiving across the life span, including for children with special needs and people with disabilities. The planning grant also allowed us to decide that the Alliance would focus on research and demonstration programs.

At the end of the grant period, the Alliance was ready to incorporate as a 501(c)(3) which it did in January 1996. The Board has decided on three initial projects: a national survey of family caregivers; a program to train nurses, OTs, and pharmacists about family caregiving; and an initiative on employed carers. With funding from GSK, Caregiving in the US 1997 was conducted in collaboration with AARP and soon took its place as the benchmark study of caregiving. The MetLife Mature Market institute sponsored the study of what caregiving cost employers in terms of lost productivity. And a program was created to train healthcare workers about caregiving.

From the beginning, the idea was to grow the Alliance beyond its initial five members. The Alliance viewed itself as the umbrella group for caregiving. NAC wanted to have a mix of national nonprofit and for-profit groups, as well as government agencies. In addition, it was decided to include professional associations, caregiver advocacy groups, and disease specific organizations - anyone who was concerned about the welfare of family caregivers and those who support them.





## History of the Carer Movement in Australia

Carers Australia has a history dating back to the early 1970s when the Domiciliary Nursing Care benefit (DNCB) was introduced, and the Council on the Ageing (COTA) successfully applied for a grant to explore care given by family and friends to the frail-aged and disabled.

Although Carers Australia didn't exist as it does today, these events were significant milestones on the road to forming the influential and authoritative organization we now have.

Another significant milestone occurred in 1980 when - in what is believed to be a world-first - the Carers Association of NSW became an independent body. This monumental shift granted the association more freedom in its advocacy work.

The Australian Bureau of Statistics used the International Year of Disabled Persons in 1981 to conduct the first comprehensive survey on disability. The Survey of Handicapped Persons gave governments and the community a deeper understanding and insight into Australians living with a disability.

Since those early days, research into caring has gone from strength to strength, and funding and programs have followed. Pensions for carers were introduced, programs were established, recognition of carers grew and more surveys and research from government and institutions were funded.

The first Carers Awareness Week was held in 1992, with the theme Carers Need Care Too! The week-long campaign was the first of its kind to raise public awareness of the important and challenging work of carers. This was followed by the first carer-focused federal budget, worth \$93 million over 4 years and including both the distribution of the Carer Support Kit and introduction of the Commonwealth Respite for Carers Program.

In 1993 the Carers Association of Australia (CAA) was launched, and in 1997 the Governor-General, His Excellency Sir William Dean, AC KBE, agreed to be National Patron of CAA. Since then, all Governors-General have accepted this role.

The following decade saw the number of conferences, campaigns, research, surveys and reports increase, demonstrating that the work of Carers Australia and the state and territory carers associations was having an effect. Awareness was growing.



**Governments were taking notice.**

**During this same period, young carers were identified as an important sub-group of carers.**

**The official launch of the Parliamentary Friends of Carers at Parliament House was held in March 2007, with Senator Grant Chapman and Anna Burke MP co-chairing the group. In 2010 The Rudd Government's social inclusion agenda identified carers under the six "Social Inclusion Priorities" and recognized young carers as "at risk of long-term disadvantage". In the same year, legislative changes to the Fair Work Bill granted parents of children with a disability under the age of 16 the right to request flexible work arrangements.**

**Whether it's as active advocates or lobbyists, or indirectly through contacts, awareness campaigns and support for carers themselves, Carers Australia in its current and previous forms has played a role in these and many other developments on the long road to improving the lives of carers, and we continue to do so.**

## **Carer Recognition Legislation in Australia**

**The rights of Australia's carers are recognized by special national, state and territory acts. This legislation underpins government strategies and policies aimed at making life easier for carers and those in their care.**

### **Rights and recognition of carers**

**The Carer Recognition Act 2010 Opens in a new window states that carers should be treated with respect and considered as partners with other care providers. This is supported by The Statement for Australia's Carers, which sets out 10 guiding principles that focus on carers having the same rights, choices and opportunities as other Australians. Australian public service agencies and government-funded service providers must ensure their employees are aware of The Statement, and that they take carers' needs into account when developing and implementing services.**

**Most states and the Northern Territory also have carer legislation. The ACT has a carers' charter and Tasmania a carer policy.**

## Useful links for Carer Recognition Legislation in Australia

» **New South Wales: Carers (Recognition) Act 2010:**

[https://www.facs.nsw.gov.au/reforms/carers/nsw\\_carers\\_recognition\\_act\\_2010](https://www.facs.nsw.gov.au/reforms/carers/nsw_carers_recognition_act_2010)

» **Victoria: Carers Recognition Act 2012:**

[http://www.legislation.vic.gov.au/Domino/Web\\_Notes/LDMS/PubStatbook.nsf/51dea49770555ea6ca256da4001b90cd/023a825c23e20790ca2579c7000fb0bb/\\$FILE/12-010abookmarked.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/51dea49770555ea6ca256da4001b90cd/023a825c23e20790ca2579c7000fb0bb/$FILE/12-010abookmarked.pdf)

» **South Australia: Carers Recognition Act 2005:**

<https://www.legislation.sa.gov.au/LZ/C/A/CARERS%20RECOGNITION%20ACT%202005.aspx>

» **Queensland: Carers (Recognition) Act 2008:**

<https://www.legislation.qld.gov.au/LEGISLTN/ACTS/2008/08AC070.pdf>

» **Western Australia: Carers Recognition Act 2004:**

<https://www.carerswa.asn.au/resources/CRA-2004.pdf>

» **Northern Territory: Carers Recognition Act 2009:**

[https://legislation.nt.gov.au/Pages/~/\\_link.aspx?id=D22AB84EF0D34827B6844503E8861562&\\_z=z](https://legislation.nt.gov.au/Pages/~/_link.aspx?id=D22AB84EF0D34827B6844503E8861562&_z=z)

» **Australian Capital Territory: Carers' Charter:**

[https://www.communityservices.act.gov.au/\\_\\_data/assets/pdf\\_file/0014/263102/ACT-Carers-Charter-Fact-sheet.pdf](https://www.communityservices.act.gov.au/__data/assets/pdf_file/0014/263102/ACT-Carers-Charter-Fact-sheet.pdf)

» **Tasmania: Tasmanian Carer Policy 2016:**

[http://www.dpac.tas.gov.au/\\_\\_data/assets/pdf\\_file/0011/306488/Carer\\_Policy\\_2016\\_new\\_ABS\\_figures\\_Feb\\_2017.pdf](http://www.dpac.tas.gov.au/__data/assets/pdf_file/0011/306488/Carer_Policy_2016_new_ABS_figures_Feb_2017.pdf)



## Formation of Carers UK

**Carers UK was one of the first carers' organizations to be started and was formally founded in 1965. The first origins of the organization started by women finding themselves in caring situations and without support writing poignant articles in the media in 1963. Media articles followed this from others in similar situations.**

**The main convener and founder of Carers UK, the Reverend Mary Webster, recognized the need for making connections immediately and for organization. She looked at three main things: 1. Media coverage raising the challenge of the situation. The second was a clear plan. The third was connecting with all those who wrote to her and made a connection. She got in touch with key researchers of the day to found the arguments and policy on evidence, fact and knowledge. Mary also aligned herself and sought the support of politicians from all parties, academics and key social policy analysts. Her message about caring was very clear and could be described as a "soundbite" in today's terms. And she developed a clear vision for what needed to change, starting with clear and deliverable recommendations.**

**The forerunner of Carers UK was launched in the UK Parliament, with cross party support in 1965. It was a membership organization of carers, who came together to seek change. It developed a clear plan and then sought funding from trusts and foundations. Within 2 years, its campaigning had gained support and the first tax reduction for those caring was secured. Today, with modern organizations and campaigns, our forms of connection through social media, the web, etc. make some of these methods of contact easier and cheaper to manage. However, the core steps of developing a campaign or organization, message, supporters, call for action, and using the media/social media as a tool, remain very much the same.**



## History of Carers Japan

**Carers Japan was established in 2010 by carers and carer advocates with the purposes of raising public awareness of family carer issues, recognizing the needs and burdens of carers, offering services and support to ease the stress and burden of carers, and advocating policy changes and schemes to support carers. Carers Japan became a general incorporated association in 2011.**

### **Mission and Activities**

**The mission of Carers Japan is to support family carers and envision a society in which care recipients and their carers can live their own lives without struggling. Carers Japan does advocacy, research and studies, policy recommendations, enlightenment, and provision of information and advice to carers.**

**While Carers Japan received no support when it started, it was the survey project supported by the Ministry of Health, Labour and Welfare (MHLW) in 2010 that gave a momentum to incorporate Carers Japan a year later. It was the very first survey in Japan regarding the current state of carers in 5 places across the country. Since then, Carers Japan has (1) conducted studies on carers and those caring about carers, (2) provided legislative, policy and other recommendations to support carers, (3) provided support programs to carers and those caring about carers, and (4) provided education and information to raise awareness of needs to support carers and to achieve policy goals. These projects were made possible thanks to the support from the MHLW, the KIRIN Foundation and Japanese Trade Union Confederation (RENGO).**

**Since its foundation, Carers Japan has been organizing a variety of studies and pioneering programs to call for a societal system to support carers, including annual Carer Support Forum, development of carer support tools and training systems, and model programs such as Carers cafés. More specific examples are as follows:**

**2010 - A study on various carers in 5 places across the country**

**2011 - A study on carers in disaster-hit areas, a study tour to the UK on support for carers**

**2012 - A study to develop a tool to support carers in a community and to develop a human resource development program, publication of Carers Handbook**



**2013 - Symposium “Young carers in their teens and 20s”**

**2014 - A study on young carers, production of a DVD “To support carers in a community”**

**2015 - A study on mutual support in communities and carers, production of Carer Support Guidebook**

**2016 - A study on young carers, a carer support forum “Caring and carer support: The global challenges”**

### **Activities in partnership with other carer support and relevant organizations**

Carers Japan consists of individual and corporate members. Carers Japan is also a member of National Association of Carer Support Organizations, promoting carer support while building a network with other carer support organizations such as Carer Support Network Aladdin. Additionally, it is one of the main members of Alliance for “No One Leaves Jobs for Care”, a group established in 2016 consisting of carer support organizations, labor unions, long-term care service providers and various other organizations.

### **Legislative advocacy**

In Japan, there is no law to support carers. While people who need care can receive a variety of services under the Long-Term Care Insurance Act (enforced in 2000) and the Act on Comprehensive Support for Persons with Disabilities, there is no systematized support for carers. Sometimes, workshops for carers are provided as optional services under the long-term care insurance system. Yet, their availability is extremely limited because municipalities are not required to provide such services. There is no assessment of carers, either. Although “Support for carers of people with dementia” is included as one of the priority issues in the national strategy on dementia, there is no national strategy that covers all of the various carers. The Child Care and Family Care Leave Act is available for working carers, with some improvements in the 2016 amendments to increase the benefit rate from 40% to 67% and to improve flexibility of the program. As about 100,000 people give up their work due to caring responsibilities, the Prime Minister and his cabinet are taking the lead in promoting policies to prevent such cases as the third arrow to realize engagement of all citizens.

These examples illustrate inadequate policies to support carers in Japan, and Carers Japan is working on advocacy to establish the Carers Act. In 2012, Citizens Action Group for the Carers Act was founded, and Carers Japan serves as its secretariat. Carers Japan also assists Liberal Democratic Party in setting up a parliamentary group for carers and provides advice to the group.

## Preparing for the First/Organizational Meeting

### *Organization*

The first meeting is an important one. It will be a time when the original conveners meet again, and it will be the first meeting between potential partners.

### *Invitations*

The invitation process can involve several components. Consider who are the influential NGO leaders in your nation. The first is contact by telephone to discuss the preliminary reasons for forming a coalition to help family caregivers. This call can be initiated by the planners seeking to form the coalition or by a subsequent contact made through networking. During these calls, organizers should take note of comments, reactions and suggestions. The calls should end with a clear understanding of the actions and who is responsible for them.

Following the initial solicitation of interested parties, a letter summarizing the details of a first meeting should be sent out. The letter can remind the potential partner of areas of common interest and possible mutual benefits.

### *Agenda and Meeting*

Before the first meeting, identify someone with a track record from the NGO sector and ask him or her to chair the meeting. The meeting should have the characteristics of all subsequently scheduled meetings and include:

- » **Start and end on time,**
- » **Have an agenda,**
- » **Use a sign-in sheet,**
- » **Provide handouts,**
- » **Make sure everyone has an opportunity to talk,**
- » **Record minutes and distribute minutes before the next meeting,**
- » **Have a comfortable meeting space and simple refreshments,**
- » **Make sure decision making strategies are implemented appropriately, and**
- » **Choose a facilitator to lead difficult discussions if appropriate.**

### *Introductions*

Have each person share their name, organization and title and answer the question of how their organization helps family caregivers or why they are interested in family caregiver issues. Allow time for this process. Persons by nature of affiliation want to share what they know, who they are, and what their organization has accomplished or is actively working on that addresses family caregiver issues. This introductory experience allows them to share that information up front and may minimize interruptions later in the coalition formation process. It is also a great introduction of the expertise, both personal and professional, that exists in the room. It is useful to even develop and distribute a brief biography on each attendee and their affiliation prior to the first meeting of the potential partners. This introduction exercise should also take place at the beginning of the strategic planning process and for new partners at the first meeting they attend.

### *Setting the Ground Rules*

The ground rules are to be identified by those gathered. Make sure that compromise and consensus building are mentioned in some way. If not, the facilitator should encourage the group to identify them as ground rules.

### *Subsequent Meetings*

Subsequent meetings should have the characteristics listed above. A review of actions identified at the previous meeting should take place.

### **Capabilities Assessment**

A survey should be conducted after the first meeting to assess the internal capabilities of the coalition. The partners should complete the capabilities review as a group. The dialogue may help inspire or remind partners of the information that may be helpful to the coalition's work. The entire group should review the information listed to see if there is consensus and if anything is missing.

Suggested questions may include:

- » **What issues face the family carer today?**
- » **What services does your organization provide to help carers?**
- » **What services do you refer family caregivers to for assistance and support?**
- » **What strengths does your organization bring?**
- » **What strengths do you as an individual bring?**

- » **What barriers do you see to the work of a coalition such as this? What solutions would address these barriers?**
- » **What previous experience have you had with collaborative efforts?**

The capabilities and capacities of the coalition help define realistic and achievable goals. Information from this capability assessment can be added to the preliminary assessment gathered as part of the formation process. The coalition may view the internal/capability assessment as a fluid process and revisit it periodically when planning projects and activities.

### **Review of Preliminary Needs and Capability Assessments**

At the first meeting, the facilitator or a member of the group should be invited to present an overview of the information gathered by the convening group in the preliminary assessment and, if applicable, the needs assessment. At subsequent meetings, the coalition may want to spend more time reviewing and discussing the preliminary assessments, as well as the capability assessment once that information has been gathered. Members should be invited by the facilitator to confirm, suggest revision or add to the assessment information. The idea in this step is to work toward a picture of the family caregiver, how she or he is doing in the community, and what services or resources are available to help.

Because family carers often fail to self-identify, it can be hard to find studies and statistics that highlight how their needs are being met and where the system is failing them. But the preliminary assessment, the needs assessment, and the capability assessment can help to define unmet needs. The gaps identified can indicate possible areas where collaboration in a state, region or nation-wide can assist family carers. Identified environmental factors and a picture of the family caregiving experience in a given community contribute to assessing the need for a community-based coalition and may indicate some initial directions for the coalition, including advocacy for legislation or educational outreach or planning to meet unmet needs. The information gathered would also help in the solicitation of funding as well as educating potential collaborators. The work you do will also identify possible areas of importance for recruiting partners.

## VISION AND MISSION STATEMENT

### *Importance of Vision and Mission*

Coalition partners need to develop agreement and have a clear understanding of why the coalition exists and their role in the coalition if they are going to be effective participants. Mechanisms to achieve these goals include the process of developing a vision and mission for the coalition and goals for action.

A clearly stated vision and mission helps all partners feel vested in coalition activities. The vision and mission identify the benefits of joining the coalition, contribute to clearly defined goals and support working relationships between the partners.

### *Vision Statement*

Every coalition needs a vision. A vision statement is a statement of your big picture dream of the way things should be. A coalition needs a vision. A vision is a global concept, our dream of the way things ought to be and a mental image of what success would look like. It is the pursuit of this image of success that will motivate the partners of a coalition to work together. The authority and vision of a few people cannot shape and drive your coalition—it must be a powerful and shared vision.

### **Sample Vision Statements:**

- » **Family carers in our nation are able to live balanced lives and have the caregiving supports and services they need.**
- » **Carers and those they care for will have the best possible quality of care.**
- » **All carers will be valued, respected, and supported and will have easy access to information, education and services.**

### *Mission Statement*

If the vision statement is the articulation of a group's dream for a bright future, then the mission statement is its declaration of purpose. Your mission is what you are going to do to accomplish your dream and why. It explains your purpose.

A clear mission statement lets outside people know what general activities your coalition will undertake and who will be the beneficiaries. It explains the problem or need your coalition is trying to address and the common values, principles or beliefs guiding it. It communicates the essence of the coalition and what makes it unique. If you encounter resistance to this exercise, emphasize the benefit of the process to the exercise.



A mission statement that incorporates or captures what has been shared should:

- » Describe what will be accomplished and why;
- » Be concise (preferably one sentence in length);
- » Be outcome oriented, stating a broad goal or goals that will be achieved;
- » Be generally worded enough to allow a broad number of strategies;
- » Give a general idea of the strategies that will be used to make a vision a reality.

**Sample Mission Statements:**

- » To improve the experience of the family carer through a one-stop source for information and referral/access to service.
- » To promote knowledge of, sensitivity to and action around caregiving issues.
- » We are dedicated to ensuring that carers' concerns are effectively recognized and addressed through advocacy, education, and empowerment.

You may wish to examine the mission statement of Carers UK, which can be found at <https://www.carersuk.org/about-us/who-we-are/mission-vision-values>

## GOALS AND OBJECTIVES

### *Developing your Goals and Objectives*

The goals of the coalition and its objectives will define and prioritize the achievable actions agreed upon by the partners - they are a vital component of how you intend to operate. These goals and objectives are born out of the vision and mission of the partnership and should be seen as the means by which they are fulfilled. In addition to consistency with the vision and mission statements, the members should take into consideration the capabilities of the coalition so that the goals and objectives are realistic and achievable. Both the goals and objectives should be developed as a group and will take some time to create and to build consensus around. Keep in mind; goals are general statements of intent. They can be long-term or short-term goals (near-term). Objectives are the practical steps needed to help you achieve your short-term and long-term goals and are designed to be measurable.

Here are some examples of both:

## Goals

- » Encourage family caregivers to self-identify,
- » Increase awareness of family carer challenges and resources,
- » Promote and provide educational and training opportunities,
- » Reach family caregivers where they are – in the workplace, hospital and clinic, and at home,
- » Provide access to a full range of services – educate, support, nurture and sustain in their vital caregiving role.

## Objectives

- » Raise public awareness of caregiving and foster self-identification by carers,
- » Strengthen services and resources to carers in my country,
- » Improve online access to information on caregiving,
- » Identify and respond to gaps in services to carers,
- » Provide quarterly networking opportunities for carers, providers of services to carers, and anyone interested in the well-being of carers,
- » Facilitate inter-agency referrals,
- » Provide carer educational programs and resource information to social service providers, health care providers, family carers, employers, corporations and businesses, and the community at large,
- » Develop an infrastructure to provide information to carers about services available in their community, and
- » Empower carers to become effective advocates through education and training courses.

## References:

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National Alliance for Caregiving (2013). *Planting the Seed: Establishing and Growing Your Family Caregiver Coalition*. Bethesda, MD: National Alliance for Caregiving.

National Alliance for Caregiving (2014). *Growing Your Coalition: What to Do After You've Planted the Seed*. Bethesda, MD: National Alliance for Caregiving.

Other useful resources include:

Carers UK (2017). *State of Caring 2017*. London: Carers UK. Available at: <file:///C:/Users/Owner/Downloads/cuk-state-of-caring-2017-report-web.pdf>



## Creating a Strategic Plan for Your Carer Coalition

### Introduction

Strategic planning is the thoughtful, organized process by which your coalition will define its strategies, direction, and make decisions on allocating its resources to pursue these strategies in order to create your future. Strategic planning takes you outside the day-to-day activities of your coalition, changing your mode of functioning from “reactive to proactive.” It stimulates creative thinking about your coalition’s future and provides you with the “big picture” of what you are doing, what you want to be doing, where you are going, and why you are going there. In many organizations, this is viewed as a process for determining the actions of the coalition over the next year (short-term) or, more typically, 3 to 5 years (long-term). The strategic planning process has the benefit of creating a strategic plan to guide the coalition’s future work.

### Why Plan Strategically?

Once your coalition has been created and the primary infrastructure is in place, it is time to plan for the future, both short-term and long-term. There are at least five compelling reasons to engage in strategic planning:

1. Allows you to chart a course for the future. The strategic plan is a roadmap which directs your organization toward future action and provides an opportunity to assume a proactive position. In other words, the strategic plan answers where your organization wants to go and how to get there.
2. Identifies the coalition’s obstacles and opportunities. This can include unmet needs, capacity to provide services or begin initiatives, and any issues related to the environment in which the coalition is working.
3. Clearly defines the overall mission of the organization and focuses on the objectives.
4. Provides a sense of direction and continuity to guide staff and leadership.
5. Provides standards of accountability for people, programs, and allocated resources.

In summary, strategic planning is the key to helping you collectively and cooperatively maintain control of the coalition’s mission, its operation and its future direction.

## Planning for a Strategic Planning Process

A strategic planning process is not something that should happen at a regular coalition meeting. It requires careful planning to ensure that the process is thorough and comprehensive. When you develop or revise a strategic plan, you are setting the parameters for the work of your coalition, usually for two to three years ahead of the coalition's current work. So, it does make sense to spend some time and energy planning for your strategic planning process.

### Timing

When determining whether the coalition should begin a strategic planning process, your organization should ask:

- » **How long should our strategic planning process be?**
- » **How often do we need to do an evaluation or update the strategic planning process?**
- » **How far into the future do we need to plan?**
- » **When should we engage in strategic planning? (e.g. Annually, Bi-annually, etc.)**

Coalitions should consider a strategic planning process when the function of the coalition needs to be developed, clarified, or consolidated. When your coalition is ready to begin the process, set aside a day or two of actual planning time. Sometimes, holding a retreat of the coalition leadership is a great way to help everyone focus. There is usually no need to do a strategic planning process more than once every three years unless something has significantly changed with the coalition or the environment. This does not exclude you from doing a strategic review more often. A strategic review is quick, where you look at the strategic framework against what is happening internally or externally, as a sort of reality check. One factor that might be helpful is aligning your strategic review with key points in time that may affect your coalition's work, like the end of a legislative session.

For more information on how to review a strategic plan, visit:

<http://mystrategicplan.com/resources/how-to-run-a-strategy-review-meeting>

### Who Should Be Involved in a Strategic Planning Process?

The convening or host organization most likely will be a disease specific organization that recognizes the importance of carers. The chair can create a committee of members to develop a draft strategic plan, discuss the establishment of by-laws, and consider the issue of obtaining a non-profit status.



It is critically important that the designated leadership of the coalition takes the lead in doing the primary planning. There may be other key stakeholders in the coalition with distinct skills and knowledge who should be invited, as well. This includes family carers, whether they are official members of the coalition or guests invited to participate in the process. Their input is valuable and their inclusions serve as a reminder that the coalition's ultimate purpose is to serve family carers' best interest. Once the plan is drafted, it is important to involve the whole coalition to have an open discussion and to generate a consensus of support around the plan.

### **Building Your Strategic Plan**

Once the coalition leadership has decided who will participate and what process will be used, your coalition can start determining the direction of the organization. To begin, it is necessary to understand the coalition's current position and the variety of avenues through which it can or should pursue a particular course of action. Generally, your coalition's strategic plan will enable you to answer the following questions:

- » **Who are we? What are our mission and values?**
- » **Where are we now? Where do we want to go?**
- » **What capacities do we have and not have? What can we do and not do?**
- » **Who do we serve?**
- » **What problems are we addressing?**
- » **What difference can we make based on existing opportunities?**
- » **Which critical issues must we respond to for the population that we want to serve?**
- » **What should our priorities be?**
- » **Where should we allocate our resources?**

A Strategic Plan is a blueprint used to communicate the organization's goals and objectives to the coalition partners and other individuals, but also the actions (or strategies) needed to achieve them and all of the other critical elements developed during the planning process. Once these questions are answered, your coalition will be able to identify its mission (the purpose of your coalition) and vision (what you hope your organization will become as it grows). Then your organization can identify the operational steps necessary to achieve your mission and vision.

To identify what steps you have to take in order to fulfill your mission and vision, ask the following questions:

- » What should our short-term and long-term objectives be (i.e. where are the opportunities)?
- » How should we organize ourselves to achieve these objectives?
- » What resources will we need to achieve these objectives?
- » What are the barriers to achieving these objectives?
- » Do we need to create standing committees (e.g. communications, fundraising, advocacy, etc.)?
- » How will we communicate the strategic plan to the broader coalition partners?
- » Who will do what, and when?
- » How do we define and measure success?
- » A strategic plan is not rigid, as it must be adaptable to respond to situational changes. It does, however, give you parameters within which to work. That is why it is important to:
- » Base your strategic planning process on a true understanding of the realities and challenges of the environment in which you are working.
- » Use your collective coalition knowledge to extend your understanding of the environment and of your coalition's capacity, strengths, and weaknesses.

In other words, the coalition should look at factors such as the economic environment of the community, the estimated number of carers in the area, local carers' greatest needs (e.g. education and training, help with transportation or respite care, state advocacy), support systems already in place (such as those available through hospitals or local departments on aging), and coalition needs, such as funding or communication capacities. Analyzing potential barriers to success will help define the needs in the community and where the coalition should be strategically working.

You may wish to examine the Strategic Plan for Carers UK. It can be found at <https://carersuk.org/about-us/who-we-are/our-vision-2021>

## References:

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National Alliance for Caregiving (2013). *Planting the Seed: Establishing and Growing Your Family Caregiver Coalition*. Bethesda, MD: National Alliance for Caregiving.

National Alliance for Caregiving (2014). *Growing Your Coalition: What to Do After You've Planted the Seed*. Bethesda, MD: National Alliance for Caregiving.

Additional resources that may be valuable to developing a Strategic Plan include:

AARP Public Policy Institute (2015). *Valuing the Invaluable: 2015 Update*. Washington, DC: AARP Public Policy Institute. Available at:

<http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>

Care Alliance Ireland (2014). *Strategic Plan 2014-2017*. Dublin: Care Alliance Ireland. Available at: [http://www.carealliance.ie/userfiles/file/Strategic%20Plan%202014\\_2017%20Pdf%20for%20Web.pdf](http://www.carealliance.ie/userfiles/file/Strategic%20Plan%202014_2017%20Pdf%20for%20Web.pdf)

Carers Australia (2015). *The Economic Value of Informal Care in Australia in 2015*. Deakin: Carers Australia. Available at:

<http://www.carersaustralia.com.au/storage/access-economics-report-2015.pdf>

Carers UK (2015). *Valuing Carers 2015*. London: Carers UK. Available at:

<file:///C:/Users/Owner/Downloads/cuk-valuing-carers-2015-web.pdf>



## Communications and Carer Coalitions

Coalitions communicate to several different audiences at various times and with various intentions. This section discusses effective ways to communicate to different external audiences, whether it be family carers, media, coalition supporters, businesses, employers, elected officials and other decision makers, or the community-at-large. The purpose of this section is to identify how your communications can further your strategic goals.

There are many reasons why coalitions need to communicate effectively, whether it is to promote an event, to advertise their work in the community, to create public awareness, or to promote systemic or other policy change. The purpose of the communication, as well as the audience, will determine which strategy is best for delivering a message.

The message needs to be understandable, it needs to capture the audience's attention, it needs to be delivered through the right channels, and, after delivering the message, the coalition needs to evaluate whether the audience understood the message. In other words, coalitions should consider when and how they want to deliver their message because each audience needs a different approach.

Effective communication starts with good planning. Thinking about your coalition's communication strategy should be part of the strategic planning process, as well as part of the coalition's everyday work to promote itself and its activities. If communication is going to be a key component of your coalition's strategy, the coalition should consider creating a communications committee with people who have experience in that field. For more in-depth information about how to plan and structure effective communication visit: <http://www.mindtools.com/page8.html#planning>

### Identifying the Audience and Crafting the Right Message

Brainstorming with coalition members to identify your audiences can be very beneficial. Your audiences will likely be broad and diverse, and may include: family carers, media, coalition supporters, businesses, employers, elected officials, and other decision makers, or the community-at-large. You should consider what each audience needs to know and wants to hear so you can craft a message that resonates. This will also help the coalition to plan when and how to deliver the message in an effective way. If you are working with people or organizations who may speak different languages, you will also want to consider

which language to use for the coalition's internal and external communications. In some cases, it may be advisable to hire a translator with expertise in cultural competence to help prepare communications that address language and cultural barriers.

Timing is very important. For instance, be sure to promote an event far in advance so participants can plan to attend. Or if you want to reach a legislator about a piece of legislation, be sure to reach out when the time is right, whether it is before a vote or when the key sponsor is seeking supporters. For advocacy work, it is important to consider when the legislature is in session while planning a communications campaign.

The message for family carers may be different than the message you deliver to other professionals or policy makers. This is because family carers will engage with your message differently than a policymaker. For example, you may ask a family carer to write to their legislator to voice support for a respite bill. In contrast, you would ask your legislator to support the bill during the legislative process.

One exercise to improve your communication planning is to develop various key messages or talking points for different audiences. Talking points summarize what you want to communicate and are intended to engage people. They are usually written in brief bullet points and plain language so that they are easy to remember.

Before developing key messages, the coalition should:

1. Revisit its goals and objectives to ensure that the messages align with its strategy, and
2. Make sure it wants to be associated with the words and phrases in the talking points.

For more information about what key messages are, why they are important and how you should develop them, visit: <http://comprehension.prsa.org/?p=4426>

Using the key messages as a guide, can be a good idea for a coalition to think about developing an elevator speech. An elevator speech is a brief, persuasive speech used to spark interest in what the coalition does. You can use an elevator speech when you have the opportunity to speak to someone with influence, resources, or other stake in the coalition in order to create interest in a project, idea, or the coalition's work generally. A good elevator speech should last no longer than 20 to 30 seconds and needs to be interesting, memorable, and succinct. For more information about an elevator speech, when to use it and how to create one, visit: <http://www.mindtools.com/pages/article/elevator-pitch.htm>



## Ways to Deliver the Message

How you deliver the message is almost as important as the message itself. It is critical to think about your audience and how they access information, so you can reach them through the most appropriate and relevant communication channels. In many cases, more than one method will be most effective.

Some common communication tools include:

- 1. Direct mail campaigns, such as writing a letter or sending a postcard,**
- 2. Electronic communications, such as sending an email or electronic newsletter,**
- 3. Online webinars or web conferences,**
- 4. Social Media (such as Facebook, Twitter, LinkedIn, Google+, Pinterest, etc.),**
- 5. Blogging, either on your website or as a “guest host” on another site,**
- 6. In-person meetings, events, or personal testimony,**
- 7. Press releases and media advisories,**
- 8. “Earned Media” or press/media coverage of your events and work, and**
- 9. Paid Media, or paid advertisements in newspapers, radio, television or billboards.**

While many of the most effective marketing tools are free or low-cost, they require a significant time commitment and planning. Many online tools offer “analytics” or analytical information to track how people are using the information you send out. For example, newsletter software can often track how many people open your emails, when they read them, and when or why they unsubscribe.

Your coalition should also consider tailoring your message for the tool and audience. For example, you may discover that policymakers follow your conversations on LinkedIn, and that family carers mostly follow your work through Twitter. In that case, your LinkedIn discussions should be targeted to policymakers with more complex content. Your Twitter feed may have more information on resources and education for family carers. Tracking the success of each method of communication will help to improve the reach that your message has among your audience.

Additionally, your coalition should be aware, when using communication techniques of certain etiquette and copyright laws. Photos that have rights reserved must be attributed according to the copyright. Content that you find online, in addition to the photos, may also have copyrights reserved. If you're not sure whether you can use content you find,



reach out to the author or organization to ask for permission. Many organizations are happy to share content, but ask that you link back to their website. Building good relationships online will help your organization find partners to share news about your coalition while moving forward.

When working with media, start by reading work from writers, reporters, and bloggers who specialize in caregiving, health care, long-term care, or the population you are working with. Begin by making a short list of writers and their preferred method of contact, such as e-mail, telephone, or even social media sites such as Twitter. Then, “pitch” your reporters the story you want to tell about your coalition. When preparing your pitch, consider the resources you can offer the writer or reporter, such as:

- » **Personal stories from family carers, who are comfortable talking to media and staying on point;**
- » **Statistics or facts about caregiving in your country or community;**
- » **Experts, who can speak broadly to the issues affecting carers. This may include both thought-leaders in the NGO space and academics who do research on caring;**
- » **Photographs or videos that help to illustrate the story your coalition wants to tell.**

When pitching a story to a reporter, be conscious that they are often under intense time pressure. Make sure to make your pitch concise, and simple, with a powerful story that matches the type of work that the reporter or writer typically does. Include your contact information, e-mail and phone, and indicate your availability for follow-up questions. As time goes on, you can develop ongoing relationships with reporters who may come to your coalition for stories in the future.



## References:

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National Alliance for Caregiving (2014). *Growing Your Coalition: What to Do After You've Planted the Seed*. Bethesda, MD: National Alliance for Caregiving.



# The Impact of Caring on Carers' Health

## Introduction

Providing care to someone in need can be a rewarding experience, but some carers may face the health risks and stress that come with it. Carers often experience a physical, mental, emotional, social, or financial toll while caring for a friend or loved one. Taking care of oneself is a priority if the best care is to be provided to others. Finding a balance between one's needs and the needs of others is essential to living a healthy and stress-free life.

## What is the Impact of Caregiving on Health?

Carer burnout is a state of physical, emotional, and mental exhaustion that occurs for some carers when a person is overwhelmed from multiple responsibilities. Anyone caring for a person whose health is deteriorating needs help and support from friends, family, and a support group. Every carer faces a unique situation, but often there are opportunities to find help from others who have been carers or are currently dealing with a caregiving situation.

## Carers Health Statistics in the United States



- 1. The toll on the carer's health appears to increase over time. Of persons providing care for 5 years or more, 20% report their health is fair or poor, compared with 14% of those who have been providing care for less than a year. Similarly, as burden rises, so too does the percentage of carers who report fair or poor health (21% high burden vs. 13% low burden).**
- 2. The carer's health is strongly correlated to his or her household income. Of carers with less than \$30,000 in household income, 30% report fair or poor health. This percentage declines sharply to 7% for the carers with household incomes of \$100,000 or more. There is a similar pattern with carer education levels and health.**
- 3. Other sub-groups of carers who are apt to say their health is fair or poor include those caring for a spouse (27% vs. 15% all other relationships) or for someone with a mental health condition (25% vs 12% not doing this).**
- 4. Younger carers, that is, those 18 to 49 years old report better health than carers 65 and older.**



## Carers Health Statistics in the United Kingdom



1. In the UK, research by Carers UK (2015) found that carers providing substantial care are twice as likely to be in bad health as those who are not caring. As in the US, carers reported delaying treatment and skipping medical check-ups due to their caring responsibilities.
2. The age profile is also different; younger carers are up to three and a half times more likely to be in bad health than non-carers of the same age. There is evidence to show that carers who don't get a break are more likely to have poor mental health. A substantial percentage of carers say that they have experienced stress-related disorders and physical injury because of providing significant care. A survey of family doctors shows that carers providing more hours of care are more likely to suffer from hypertension.
3. Carers UK completes an annual survey looking at some of the key challenges around caring. This is published in the State of Caring survey, which can be found at <http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017>

## Carers Health Statistics in Ireland



Research conducted by Care Alliance Ireland (2008) indicated that family carers were less likely to state that they were in excellent or very good health than the general population. These carers reported high levels of depression, back pain, and anxiety. Another study by Care Alliance Ireland (2009) indicated that 71% of the carers reported their health as quite good or very good; yet, over half of them indicated that the caring role "drained" them physically and mentally.

## What Can Carers Do to Avoid Burnout?

- » Do not blame yourself for feeling stressed or overwhelmed.
- » Set boundaries with the person you are caring for and learn how to balance the time you devote to caregiving and the time for your personal needs and your family.
- » Realize your limitations and make realistic goals for yourself.
- » Ask for help or allow help from family and friends.
- » List your priorities and organize your duties. Keep a list of tasks you have to do and ask for help where you need additional support.
- » When undertaking a long and exhausting task, be sure to take breaks.
- » Live one day at a time.
- » Exercise whenever you have time. Exercise can reduce stress and increase energy.
- » Take naps or sleep more at night.
- » Set aside time for meditation or prayer.
- » Set aside time for any hobbies or community activities.
- » Eat nutritional and healthy meals.
- » Treat yourself to a massage or other relaxing activity.
- » Socialize with family and friends. Consider reaching out to community organizations that can provide an outlet and place to socialize.
- » Use respite care when needed.
- » Get help with practical tasks.
- » Obtain advice and information about your financial situation. Are there entitlements you can claim which would help improve your finances, or the income of the person for whom you are caring?

## How Can Carers Get Help?

- » Family members and friends may often be a great source of help, but may not understand what is needed or know how to help.
- » Contact an agency, organization, or support group that may be able to help you or your recipient with caring. If there is no carer organization in the area, see if there is a patient or disease-specific organization.
- » Contact government representatives in the health and human services division of your locality, province, or nation. Ask if there are resources available for carers.

## Carers and Depression

### Symptoms of Depression

- » Irregular sleep patterns,
- » Feeling drowsy or down throughout the day,
- » A loss of interest in people and/or activities that once brought you pleasure,
- » Becoming easily frustrated or angered,
- » Feeling disappointed in yourself for no particular reason,
- » Thoughts of death or suicide.

### Dementia and Care

Carers who care for someone with dementia or Alzheimer's are twice as likely to suffer from depression compared to other carers who care for non-dementia recipients. Caring for someone with dementia can be a stressful and time-consuming situation. It is important for carers to see a doctor if they think they have depression. Depression is a serious condition that affects many family carers.

### Carers' Health Changes

The psychological and emotional health of the family carer is sometimes negatively affected by providing care. Providing care may amount to increased levels of stress, anxiety, depression and other health effects that are typical in family carers.

- » In the US, 20% of carers feel that caring has made their health worse (*see Caregiving in the US – 2015*).
- » Higher-hour carers are more likely to feel caring has had a negative impact on their health (29% vs. 18% of lower-hour carers).
- » Those caring for a close relative, such as a spouse or parent, are at a much greater risk of declining health as a result of caring.
- » Carers in more complex care situations are more likely to report their health has suffered because of providing care. These carers include those caring for someone with a mental or emotional health issue (34%), co-resident carers (30%), and those providing medical/nursing tasks (27%).



## Physical Strain of Caring

Carers are often at risk of having physical health problems, just as much as emotional health problems. Helping recipients with the activities of daily living such as bathing, grooming, and feeding can put a physical strain on frail or stressed carers.

One in five carers report a high level of physical strain as a result of their caring duties (19% rating a 4 or 5 on a 5-point scale). One in four experience a moderate strain (26% rating a 3), while about half feel little physical strain (54% rating 1 or 2).

High burden carers, Alzheimer's or dementia carers, co-resident carers, long-term carer providers, and older carers (65+) are all more likely to report a high degree of physical strain.

## Emotional Strain of Caring

- » Forty percent of carers consider their caring situation to be highly stressful.
- » Nearly half of higher-hour carers find their role emotionally stressful (46%), more so than lower-hour carers (34%).
- » The NASEM report on caregiving indicated that 13% of all caregivers and 15% of those caring for the most disabled older adults reported symptoms of anxiety and depression. Dementia carers report significantly higher rates of depression.
- » Caring for a close relative such as a spouse or parent is more emotionally stressful than caring for a distant relative or non-relative.
- » Chronic or long-term conditions among care recipients seem to be particularly likely to cause emotional stress in carers.

## Financial Strain of Caring

One in five carers report experiencing financial strain as a result of providing care. Higher-hour carers are more likely to indicate that they experience financial strain, than lower-hour carers. Similar to emotional stress, co-residence seems to create financial strain most often for higher-hour carers.

- » Carers who live farther away from their recipient are more likely to report higher levels of financial strain.
- » The longer a carer has been caring, the more likely they are to feel financial strain.

## Assistance with Medical/Nursing Tasks

Recent research in the US, *Caregiving in the US – 2015*, revealed that family carers are increasingly performing tasks that nurses typically perform. These medical/nursing tasks include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities. Fifty-seven percent of carers assist with these kinds of tasks and many indicate that they have been inadequately instructed, which increases their stress and burden.

## What Can Carers Do to Take Care of Their Own Health?

- » Make sure you receive annual immunizations and an annual physical examination from your health care practitioner.
- » Learn new information from articles, books, or fact sheets regarding your care recipient. In addition, utilize any available resources to overcome the challenges you face.
- » Learn about any available resources that can offer support.
- » Plan ahead of time to know what supplies and resources you need to take care of someone.
- » Develop contingency plans for emergencies and obstacles.
- » Ask and accept help. Do not take on responsibilities that are more than you can handle alone.
- » Take care of your health first before helping others.
- » Get enough sleep, and eat and hydrate regularly.
- » Set aside time for yourself every day, focusing on your needs and priorities.
- » Make time for leisure activities. Enjoy a hobby, go to the cinema, take a walk or jog outside, or take part in any stress-free activities you enjoy.
- » Maintain a sense of humor. Laughing is a fun and healthy activity. Joking around, going to see a comedian, or watching a funny movie are all ways to make you laugh and lighten the situation you are in.
- » If you are religious or spiritual, taking time to devote to these events may help cope with the difficulties you face.
- » Do not be frustrated with yourself.
- » Talk with others about the stress or responsibilities you are going through. It may be beneficial to join a support group and discuss your difficulties with others going through the same experiences.

**Engaging in any of the following increases a carer's risk for health problems dramatically:**

- » Binge eating,
- » Alcohol or recreational drug abuse,
- » Smoking cigarettes or chewing tobacco,
- » Sedentary lifestyle or lack of exercise.

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# Caring and Employment

## Introduction

In the United States, two-thirds of carers work away from home. This presents a challenge for working carers and their employers. Three-fifths of carers are in the workforce. A majority of working carers are full-time employees and average almost 35 hours a week. Handling the responsibilities of caring for a loved one and having to work can be time-consuming and stressful. It also forces working carers to turn down new career opportunities, job promotions, training, quit their jobs, or consider early retirement. Employers then face the costs of replacing invaluable employees. By working together, employees and employers can create a workplace environment that is productive and meets everyone's needs.

According to the 2011 UK Census, one in nine residents in the workforce is caring at any given time. Around one in six families who are juggling care for a disabled or older relative also have children under the age of 18. Relatively new research in the UK shows that even just five hours of caring per week can begin to have an effect on employment.

## Impact of Caring on Employed Carers

Research in the United States and other nations has found that working carers of aging relatives report having less access to flexible work options to carry out their work and caring responsibilities, and perceive significantly lower job security than workers with routine childcare needs. Carers in the US who provide support 20 hours or more per week for a loved one often have to cut back on hours or quit their job altogether. Family carers may forego earnings and Social Security benefits if they cut back on work hours or quit their jobs to provide care. They can also lose job security, career mobility, and employment-related benefits such as health insurance and contributions to retirement plans.

### Employed Carers:

- » Are more likely to report fair or poor health in general.
- » Are more likely to report depression, diabetes, hypertension, or pulmonary disease.
- » Find it more challenging to take proper care of their health while caring for another.



### How Employed Carers Can Get Help

- » See what rights and entitlements exist in the workplace and determine if there is an Employee Assistance Program.
- » Check whether there is any support, including technology, that might help you manage care better – particularly if you need peace of mind while at work.
- » Contact the suitable disease-related organization such as the Alzheimer's Association or the Diabetes Association. Organizations similar to these can help guide carers to useful resources such as educational programs and support groups.
- » Look at fact sheets, brochures, and up-to-date news concerning caring.
- » Investigate what services are offered by your employer and determine if they may be of use to you and your relative.

### Balancing Work and Care

- » Find a balance between time at home and time at work.
- » Share your household or caring duties with others around you. Do not be timid asking others to help you. You have every right to ask for help.
- » Spread awareness of the struggle carers face, with your employer or place of business. Ask them to recognize your needs and the needs of other employed carers.
- » Communicate with your employer or Human Resources Department about the challenges you are facing as a carer.
- » Use any available resources your company has to offer. Every business wants and needs the most efficient workers. Companies want to provide support for their employees.
- » Go on vacation. If possible, take time off from work and use it to focus on your well-being. Make time for yourself. Spend time with alone, or with friends and family. Be sure to include activities that are important to you.
- » Identify resources in your community.

### Cost of Caring to Employers

The more experienced a staff member, the higher the costs of replacing them if they leave. Employees are more likely to become carers between the ages of 45-64. Failure

for a business to retain these experienced workers could result in a substantial loss of resources and knowledge. Experienced workers are essential to the growth of a business. Carers are more likely to stay with an employer if their needs for flexibility are met. Implementing carer-friendly policies is an important investment in employee retention.

Businesses in the United States lose up to an estimated \$33.6 billion per year in lost productivity from full-time working carers. Costs associated with replacing employees, absenteeism, workday distractions, supervisory time, and reductions in hours from full-time to part-time all take a toll. In the United States, the average annual cost to employers per full-time working carer is \$2,110. In the United Kingdom, Employers for Carers is an employer led forum operated by Carers UK, with over 130 members. It has a clearly articulated business case describing why carers should be supported in the workplace. For more information, go to <http://www.employersforcarers.org/business-case>

### **The Benefits of a Business Becoming a Carer-Friendly Workplace**

- » Reduce costs of employee turnover,
- » Increase employee morale,
- » Increase staff efficiency,
- » Improve service delivery,
- » Reduce employee stress and increase worktime attendance,
- » Attract quality workers,
- » Build a resilient workforce, and
- » Improve health and well-being at work.

### **Other Options or Programs Employers Can Implement to Help Carers Include:**

- » Paid Time Off (PTO) Programs- This program is designed to replace traditional programs (vacation, sick, personal days) with a single time block that allows employees additional control over their time off.
- » Telecommuting Arrangements - Businesses help employees balance work and home to improve retention, loyalty, and productivity by allowing carers to work remotely.
- » Stress-reduction seminars, expanded to include yoga and exercise classes, relaxation techniques, and massage therapy.

- » Decision-support systems to reduce stress among carers by informing them about the services offered to them and their family members.
- » Financial incentives to encourage employees to take advantage of preventative health care benefits offered by employers (reductions on premiums or deductibles (for carers in the US).
- » Expanded on-site medical testing and screenings.
- » Online support groups for employees.
- » Health coaching services and nurse hotline access.

### Potential Employer Responses

Studies have documented that implementation of eldercare programs can benefit both employers and employees. Eldercare programs improve worker retention, productivity, stress levels, and health among workers. Some businesses offer carer fairs, line supervisor training, lunchtime seminars, flextime and shared work, as well as dependent care accounts. Others provide assistance with referral to carer resources in the community, on-site support groups for working carers, and discounted backup home care for emergency needs.

Employers have found eldercare benefits to be a competitive advantage both in new employee recruitment and retention of existing employees:

- » **Carers may need access to flexible working arrangements in order to combine work with an unpaid caring role. This may involve different start and finish times, the option to work from home occasionally, or perhaps a shorter working week while still completing the hours of a full-time position.**
- » **Alternatively, carers may need flexible leave arrangements for planned or unplanned caring responsibilities. Leave arrangements may include compassionate or carer's leave for emergency or planned caring, or they may allow carers to take a combination of paid and unpaid leave in order to fulfil caring responsibilities.**
- » **A workplace culture in which employees feel comfortable and are encouraged to request (and utilize) flexible working provisions without the fear of reprisal or other negative repercussions from management –but also other employees – is essential.**
- » **Supporting carers in the workplace could involve setting up a carer's network within the organization or distributing information about how to find caring support in the community.**

## **Workplace policies that support and accommodate carers show business benefits.**

Numerous studies have found that flexible workplace policies enhance employee productivity, lower absenteeism, reduce costs, and appear to positively affect profits. They also aid with recruitment and retention efforts, allowing employers to retain a talented and knowledgeable workforce and save the money and time that would otherwise be spent recruiting, interviewing, selecting, and training new employees.

In addition to specific eldercare benefits, flexible work options, family leave and paid sick days are vital policies for working carers. These workplace benefits can help working adults balance their work, personal lives, and family caring responsibilities.

## **Employed Carer Rights in Other Countries**

The Fair Work Act of 2009 in Australia grants carers the right to annual leave entitlements to cover sickness or caring responsibilities, such as the right to negotiate an individual arrangement that changes the conditions of your modern award or enterprise agreement to meet a genuine need. The Carer Recognition Act of 2010 recognizes that carers should have the same rights, choices and opportunities as other workers, and requires Australian Public Service agencies with programs and policies directed to carers, or the people they care for, to consult with carers and report each year on what they have done to better support carers.

In 1993, the United States passed the Federal Family and Medical Leave Act which required companies with more than 50 employees to offer 12 weeks of unpaid leave to employees who need to care for sick children, parents, spouses, or themselves.

In the United Kingdom, all employees, including carers, with at least 26 weeks of employment, have the right to request flexible working. There is also a right to take an “emergency unpaid leave” to care for dependents - this is usually a matter of one or two days and is not a well-known. There is also legislation in each of the countries in the UK: England, Wales, Scotland and Northern Ireland which gives carers a right to an assessment of their needs. The assessment must also include a consideration of whether they wish to work and remain in work. This covers adults caring for adults, as well as those caring for children with disabilities. It also places a duty on local authorities and the Health Service Executive (HSE) to inform carers of their rights. The Care Act of 2014 sets out carer’s legal rights to assessment and support. The Act also contains new rules about working with young carers or adult carers of children with disabilities to plan an effective and timely move to adult care and support.

The Carer's Leave Act in Ireland allows employed carers to take a leave from their job in order to care full-time if the person receiving care is determined to need someone to provide him/her full-time assistance. A carer can take a leave from 13 weeks to a maximum of 104 weeks. The leave is unpaid, but the employer must keep the carer's job open for him/her to return to it. Carers may be eligible for a Carer's Benefit if they have made sufficient contributions or if they otherwise qualify for this means-tested payment. The person receiving assistance from the carer can be a family member, friend or colleague. More information can be found in the Carer's Leave fact sheet from Citizen's Information. To access the fact sheet, refer to the following link: [http://www.citizensinformation.ie/en/employment/employment\\_rights\\_and\\_conditions/leave\\_and\\_holidays/carers\\_leave\\_from\\_employment.html](http://www.citizensinformation.ie/en/employment/employment_rights_and_conditions/leave_and_holidays/carers_leave_from_employment.html)

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# Young Carers

## Introduction

Young carers are children and teenagers who look after someone in their family who is elderly, frail, disabled, or has a physical or mental illness. In some countries, people up to 25 years of age, are categorized as young carers. Young carers often take on the physically and/or emotionally demanding responsibilities that are typically expected of an adult. The duties that young carers assume vary by the health of the person that he or she is looking after.

It is important to remember that young carers helping to look after a sibling are often overlooked. Likewise, not every child whose parent or sibling is ill or has a disability is necessarily a young carer. Regardless of the level of care, young carers take on a difficult and challenging task at a young age, and while still enrolled in school.

## What are some duties that young carers undertake or perform?

- » **Providing emotional support.**
- » **Managing the family budget, collecting benefits, picking up prescriptions, and running other errands.**
- » **Practical tasks, such as cooking, cleaning, and shopping.**
- » **Physical care, such as lifting, helping a family member travel on a stairwell or with rehabilitation.**
- » **Looking after younger siblings or older relatives.**
- » **Interpreting, due to a hearing or speech impairment.**
- » **Personal and intimate care tasks, such as feeding, dressing, bathing, brushing teeth, and helping with toileting needs.**
- » **Administering medication in the forms of pills, injections, oxygen, treatments, etc.**

A young carer may become overwhelmed when the level of care becomes excessive or unsuitable for the child, impacting his or her emotional or physical well-being as well as educational achievement and future success.

Aside from undertaking the responsibilities of caregiving, youth carers also have an array of other activities that they perform. These activities often have a negative impact because of how time-consuming and exhausting caregiving tasks can be.

**Youth carers often experience the following problems:**

- » Completing homework assignments,
- » Studying for exams or tests,
- » Focusing on getting good grades,
- » Socialization with peers because they cannot leave the parent or sibling without support, or they are unable to invite friends to their own home,
- » Participating in after-school clubs or activities,
- » Competing in athletic or sport events,
- » Socializing with friends and other students at school,
- » Taking proper care of themselves and identifying their own needs,
- » Volunteering or part-time employment.

### **How can you determine if a child or teenager is a carer?**

Teachers, school officials, and social workers are able to recognize children and teenagers that are also carers. If asked whether they take on any caregiving responsibilities, young carers will at times be uncommunicative or deny their role in providing care. This is common among younger carers, who may feel embarrassed to admit that they are a carer. Some may also be reluctant to admit being a carer due to concerns that the child welfare system might view their family as dysfunctional, and remove the child from the family. Also, some young- carers deny their caring role because they fear being bullied by other children. Psychologists both in and out of the school system can work with teachers, nurses, and social workers to help identify these children and teens.

### Signs that a child or teenager is a carer:

- » Decrease in school performance,
- » Increase in tardiness or absences,
- » Changes in social behavior such as disruptive behavior, yelling, fighting, etc.,
- » Changes in mood such as anger, frustration, anxiety, etc.,
- » Increased worrying about self and/or family, e.g., anticipating bad outcomes, self-blame, etc.,
- » Fatigue or extreme sleepiness,
- » School drop-out,
- » Inability to participate in extra-curricular activities or sports,
- » Being bullied, or at times bullying others.

### Hidden Carers

Young carers remain hidden for many reasons including:

- » They do not realize that they are a carer or that their life is different from that of their peers.
- » Parents do not realize that their children are carers.
- » Worry that the family will be affected and family members or themselves will be taken into care.
- » They don't want to be any different from their peers.
- » Their parent's condition is not obvious so people don't think that they need any help.
- » There has been no opportunity to share their story.
- » They see no reason or positive actions occurring as a result of telling their story.

### What are some challenges that young carers face?

Poverty is a tragic reality for many young carers living in families suffering from chronic illness or living with a disability. Even for families where the parents or guardians are employed, medical expenses may be burdening, and living in rural areas can result in

less choices and additional expenses. Families who rely on government assistance often find themselves on a tight budget.

## Youth Carers and Education

### Attendance

Caring responsibilities can lead to tardiness or absence from school. Patterns of missed attendance can sometimes be a sign that a youth is providing a caring role. Young carers can struggle when juggling these two roles. These children make gigantic efforts to manage their caring responsibilities and maintain school attendance. However, some may struggle to balance school and caring, resulting in lower grades and possibly affecting their physical and mental health.

Young carers often say that when forced to choose between staying at home to look after the person they care for and going to school, caring will come first. They often miss after-school activities to rush home and look after a parent, or collect younger siblings from school. Conversely, punctuality can also be compromised when young carers have to transport younger siblings to school.

Inadequate support in the home for the person needing care can lead to the young carer missing school to care for a parent for example, by carrying out tasks that need to be done or by supervising them. This can create isolation from peers and from friends, and the young carer may then prefer to stay at home where they feel valued and safe.

Many young carers in their teenage years will work to contribute to the family income, which may result in lack of attendance in school. Young carers living in poverty and/or rural areas are most likely to skip school, as well as have unsatisfactory or poor academic performance.

### Addressing Attendance Issues

Patterns of non-attendance are often an indicator of a young carer's underlying need, such as insufficient support for a parent during the day. Schools should also look for and address secondary barriers to learning that may stem from a student's caring role, such as anxiety or bullying which can then reflect on attendance.

By working alongside students and their families, schools can help address needs and resolve the underlying causes of absence. Ensuring that support is in place is paramount.



If the person with care needs has appropriate support in place, students should feel more confident coming to school and less anxious about leaving the care recipient.

The family may welcome efforts to advocate on their behalf for better support arrangements to be in place. The school should respect a family's decision should they be unwilling to discuss support needs. Furthermore, it should, nevertheless, consider and address the student's welfare using their usual assessment procedures. It is vital that schools balance a supportive, flexible approach towards the young carer and their family alongside the consistent message of the importance of education to the student.

In addition to missing school, young carers may well be missing out on after-school clubs and activities (because of transportation issues, having to return home promptly to care for someone at home, or to pick up or look after siblings). Drawing up an emergency plan for a young carer may help prevent future school absence.

### **Addressing other issues that young carers face**

Young carers often go unnoticed in their communities, but the negative impacts of caring on young people can be very real and enduring. If left without any support, young carers can take on responsibilities that will have a lasting impact on their health and wellbeing, friendships and life opportunities.

Many young carers experience problems with their:

- » **Physical health:** often severely affected by caring through the night, repeatedly lifting a heavy adult, poor diet and lack of sleep, etc.
- » **Emotional wellbeing:** stress, tiredness and mental ill-health are common for young carers
- » **Isolation:** different or isolated from their peers and with limited social opportunities
- » **Lack of a stable environment:** traumatic life changes such as bereavement, family break-up, losing income and housing, or seeing the effects of an illness or addiction.

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# Rural Carers

## Introduction

Providing care to a friend or family member in need can be a fulfilling and meaningful experience, but carers often may face the stress and health risks associated with it. Providing care could result in an emotional, financial, social, and/or physical burden. Taking care of oneself is a priority if a carer wishes to provide the best care to their loved one. Frequently, carers feel overwhelmed by the responsibilities of caring for another person. There are a number of different services that a carer could use to ease their caring burden. However, for carers living in rural areas, services are either limited or inaccessible.

## Who are rural carers?

Rural carers are carers living in more secluded parts of a country. They typically face more problems than carers living in urban areas, which could result in higher amounts of stress and anxiety, and increased health risks. Rural carers carry the challenge of caring for a loved one in an isolated environment where there is often a limited access to resources and services.

Carers living in rural parts of a country typically have fewer education opportunities, financial resources, health and social services, public transportation options, and a lower life expectancy than most people living in urbanized areas. These problems leave rural carers at a greater disadvantage than most carers. There are significant disparities in health conditions with rural carers compared to suburban/urban carers. Negative health effects/conditions prevent a carer from taking proper care of a loved one, if employed, and working to maintain current lifestyle.

It is often the case that the care responsibility is increased due to the fact that adult children are likely to have left the area due to education or employment opportunities. Support from adult children is likely to be intermittent at best. Coupled with limited access to formal services that are not likely to be located in their rural area, these carers are likely to be providing care exclusively on their own without support from other family members or professionals. However, there is some evidence that networks of support within rural areas based on fictive kin can substitute for that of the family members who have relocated.

### **Areas of concern for rural caring:**

- » Availability of using internet and other technologies,
- » Financial struggles due to low income is often associated with rural carers,
- » Limited availability and use of services,
- » Prevalence of disabilities due to lack of sufficient health care or rural dangers,
- » Significant impact of caring at rural workplaces,
- » Stress from rural caring and related coping mechanisms.

For carers and care recipients, not only is the limited access to primary and emergency health care a problem, but it is compounded by limited access to other services that could be beneficial such as social, volunteer, and in-home supportive services. Rural carers face many challenges such as feeling isolated, separation from extended family, lower standard of living, and lack of transportation.

### **Resource Shortage**

Living in a rural area makes the already difficult task of caregiving even more of a struggle. One of the biggest problems carers in rural areas are facing is a lack of medical and health services. There are fewer adult day-care centers and in-home health services, such as respite care or meals on wheels. People living in rural areas struggle to find and retain qualified medical and social service professionals.

Transportation represents another difficulty for carers in rural areas. Economic migration means there are fewer young family members available in the area to provide care or to assist the primary carer. For some rural carers, the nearest health professional or hospital may be hundreds of miles away. Thus, many older persons and carers look to friends, neighbors, and the local community for caregiving support.

### **How do lower income levels affect rural carers?**

Carers living in rural areas or regions tend to be less employed than their urban counterparts. Generally, employed rural carers earn less income than non-rural carers. Also, rural carers tend to have a lesser education status and are primarily blue-collared workers. The financial hardship that many rural carers face could result in less time caring and more time working.

### What are some resources, services, or programs that could benefit rural carers?

- » Educational services and resources provided by universities and service providers focused on rural issues and caregiving,
- » Mobile adult day programs that provide respite to the rural carer,
- » Telephone and on-line support groups,
- » Technological supports such as web-based education and chat rooms focused on caregiving,
- » Telehealth to connect carers and care recipients with health care professionals for remote, monitoring of vital signs, counseling, and advice on questions regarding treatment regimes.

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# Assessment of Carer Needs

## Introduction

Carer assessment is an organized process of collecting information about a carer's situation to help identify his or her own specific problems, needs, strengths, and resources, as well as the ability of the carer to contribute to the needs of the care recipient.

Effectively assessing and addressing carer needs can maintain the health and well-being of carers, sustain their ability to provide care, prevent or postpone nursing home placement, and produce better outcomes for the care recipient. Provision of support services needed by the carer can lead to improved outcomes for the carer and his/her loved one(s).

Carers who have their needs assessed often feel more acknowledged, valued, and better understood by health care professionals. Providing the best care possible for the care recipient often requires an assessment of the family carer's situation and needs. An effective carer assessment that is conducted by a health care or social service professional, should approach care issues from the carer's viewpoint and culture. An important factor of the carer assessment process for family carers is to have someone to talk to about their circumstances and the needs of the care recipient.

## Definition of Carer Assessment

In 2006, the Family Caregiver Alliance in the United States, convened a National Consensus Conference on Caregiver Assessment. At the conclusion of the conference, the attendees agreed on the following definition:

"Caregiver assessment refers to a systematic process of gathering information that describes the caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from the caregiver's perspective and culture, focuses on what assistance the caregiver may need and the outcomes the family member wants for support, and seeks to maintain the caregiver's own health and well-being."

The Consensus Conference attendees identified seven principals to guide caregiver assessment:

- » “Because family caregivers are a core part of health care and long-term care, it is important to recognize, respect, assess and address their needs.
- » Caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.
- » Caregiver assessment should result in a plan of care (developed collaboratively with the caregiver), that indicates the provision of services and intended measurable outcomes.
- » Caregiver assessment should be multidimensional in approach, and periodically updated.
- » Caregiver assessment should reflect culturally competent practices.
- » Effective caregiver assessment requires assessors to have specialized knowledge and skills. Practitioners’ and service providers’ education and training should equip them with an understanding of the caregiving process and its impacts, as well as the benefits and elements of an effective caregiver assessment.
- » Government and other third-party payors should recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities.”

### **Who Should Conduct the Assessment?**

Carer assessments are usually conducted by a nurse or social worker, or other persons who are deemed qualified. Depending on the complexity of the care needs, other disciplines can be brought in for consultation or involved after the care plan is developed. The assessment should be conducted in a quiet, private environment. Ideally, a person with a disability, ill or older person receiving care should not be present to enable the carer to speak frankly about the care needs and their willingness to perform them.

If possible, the same individual should contact the carer at periodic intervals, ideally at three or six months. This contact is designed to determine if there are any changes in the patient’s care needs or if the health and ability of the carer has deteriorated. This is of crucial importance for elderly spousal carers. If the caring situation has changed, a reassessment should be conducted.

## What Should the Assessment Include?

- » Demographics on the carer and care recipient (age, sex, education, employment, living arrangements, other family members).
- » What is the relationship between the carer and care recipient?
- » Care recipient's health and functional status.
- » Impact of caregiving on carer's emotional/physical health, finances and employment.
- » How long has the carer been providing care? (weeks, months, years)
- » How many hours per week does the carer spend caring for their loved one(s)?
- » What is the carer's health?
- » What other caring and family responsibilities does the carer have?
- » What opportunities does the carer have for education and learning?
- » Do the carer and the person receiving assistance reside in the same home?
- » Activities of Daily Living and Instrumental Activities of Daily Living provided by the carer. What is the carer's confidence in providing these tasks? Is training needed?
- » What services does the carer currently receive?
- » Do any other family members or friends assist the carer?
- » How are services supported financially?
- » What services does the carer need?

### This may include:

- » Information and referral
- » Respite and breaks from caring
- » Volunteer Services
- » Educational
- » Carer support groups
- » In-home services
- » Case management
- » Counseling/social work
- » Meals on wheels
- » Transportation
- » Financial assistance
- » Legal advice/assistance
- » Health services and advice on technology that might support health
- » Other

## Carer Needs Assessment Research Study

Under the leadership of Care Alliance Ireland and Family Carers Ireland, an international group of researchers, Irish health and social service providers, NGO family carer organizations and family carers are modifying and field testing the interRAI Carer Needs Assessment tool in several nations. This tool is designed to allow family carers to identify their needs, be given information and advice, explore difficulties they may experience and make contingency plans if they fall ill or unable to continue to provide care. The tool can provide timely feedback to health and social care professionals and be used to inform policy and service provision.

interRAI is currently used in over 30 countries. The pilot is being implemented in 8 nations: Ireland, Belgium, Lebanon, the United States, Estonia, Hong Kong, Korea and the Netherlands. It is anticipated that project results will be released in 2018.

More information can be obtained from Liam O'Sullivan, who can be reached at [ndo@carealliance.ie](mailto:ndo@carealliance.ie)

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# Respite Care

## Introduction

Caring for a loved one can be a demanding responsibility, both physically and emotionally. Respite provides a much-needed break to carers. It allows the carer time off to relax, tend to other needs, or enjoy any activity while their loved one is still receiving the quality care that he or she needs. Respite services support the family while protecting the health and welfare of both carers and care recipients.

## What types of respite services are available?

There are different types of respite care available. The carer selects a provider who will take care of a care recipient on a regular or irregular basis. Respite can vary in time from a few hours of the day to several weeks. Respite encompasses a wide variety of services including traditional home-based care, as well as adult day care, skilled nursing, home health, and short-term institutional care. More specifically respite care may take any one of the following forms:

## In-Home Respite

The recipient is supervised and assisted by a trained individual. There are different types of in-home respite. This care can last from a few hours a night to a regular basis (daily, weekly, or monthly), depending on needs.

- » **Companion Services:** Provides companionship and monitors recipient's activities for their safety.
- » **Homemaker Services:** Assists with laundry, shopping, preparing meals, and cleaning.
- » **Personal Care Services:** Provides daily living assistance such as bathing, dressing, grooming, toileting, and exercising.
- » **Skilled Care Services:** Assists the person needing care with medication or medical/nursing services.

## Day Respite

Recipient is placed in a care facility, such as an adult day center, where they attend either half days or full days. The staff in these facilities are trained to assist recipients with



any problem they may have. Staff lead planned activities to keep the recipients occupied. Meals and snacks are available for recipients, and transportation is often provided.

### **Residential Respite**

Persons needing care attend a skilled care home for a longer period of time such as overnight, a couple of days, or a few weeks. This is similar to an adult day center except it is for long-term stay. Recipients are cared for in a supervised and safe environment. The advantage of this model is that the specialized facility will probably have better access to emergency facilities and professional assistance, if needed. This is often used to allow carers to take a vacation, attend a wedding, or if the carer is ill or hospitalized.

### **Out-of-Home Respite Services**

Respite services are provided in the community at diverse sites, and by service providers which operate licensed residential facilities or bill under a category called respite. Finally, in some areas there are organizations that match volunteers with carers to provide short-term respite.

Respite services are typically obtained from a respite vendor, through the use of vouchers and/or alternative respite options. Vouchers are a means by which a family may choose their own service provider directly through a payment, coupon or other type of authorization.

### **Emergency respite**

There may be the need for respite care on an emergency basis. When using emergency care, the carer has already identified a provider or facility to call in case of an emergency. Many homecare agencies, adult day care, health centers, and residential care facilities provide emergency respite care.

### **Therapeutic adult day care**

Therapeutic adult daycare may provide respite care during business hours five days a week. However, in some instances, this care may also be provided 24 hours a day. Usually, these are facilities for specialized clients only, and not related to family support services, other than any specialized service is considered a family support to the family which desires it.

In some areas, for example the UK, there are specialized respite care services where additional care is provided so that the family can remain together, but the carer does less of the hands-on caring tasks. In the UK, this is referred to as "taking a break." Carers UK has a leaflet that explains the different types of breaks and how to get them.

<http://www.carersuk.org/help-and-advice/health/looking-after-your-health/taking-a-break>

## What is the Cost of Respite Care?

The cost of respite care varies per country. For instance, in the United States the cost of respite care varies with the type of agency, frequency of care and the services needed, but the federal and state governments may help to pay for it. Other countries have similar programs, such as Australia, where the federal and state governments pay for almost the entire cost to eligible clients.

Respite programs provide planned short-term and time-limited breaks for families and other unpaid carers of children with developmental difficulties and adults with an intellectual disability, in order to support and maintain the primary caregiving relationship. Respite also provides a positive experience for the care recipient.

## Why Utilize Respite Care?

Caring for a loved one 24/7 can begin to wear on your physical and mental health. You may find yourself:

- » Losing your appetite or skipping meals,
- » Experiencing difficulty sleeping,
- » Feeling ill or fatigue,
- » Having headaches or migraines, and
- » Resenting the person receiving care.

## Benefits of Respite Care:

- » Offer relief, leisure time, and get-away,
- » Prevent the build-up of resentment,
- » Improve the health and happiness of the carer and loved one, and
- » Allow the carer to feel rejuvenated and refocused.

Depending on the carer's needs, as well as those of the person needing care, a respite care worker will come to the home for a few hours. These visits could be once a week, or more frequently. While the respite care worker tends to the person needing care, the carer is free devote time to themselves. The respite can be used to meet friends for lunch, catch up with sleep, attend a hair appointment, see a physician, or even to read a book in the backyard. This is the carer's time to rest and recover.

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# Adult Day Services

## Introduction

Adult day service centers offer much needed relief to a family carer by providing temporary care to a loved one. Adult day service centers deliver social and health services to aging adults and persons with disabilities in a safe, community environment. These centers allow the carer to take a break from the demanding responsibilities of caring and continue employment, or use the time for medical appointments or other tasks.

Carers are comforted with knowing their loved one is receiving care and being properly supervised. Carers are given the opportunity to work, perform other duties, or time to relax. Adult day services are a care option that allows individuals to remain in their homes, rather than require assisted living or live in a nursing home. These centers are typically a less expensive alternative to other types of care. They are typically open five days a week operating during normal business hours. However, some centers have flexible hours (they may remain open at night or on the weekends), to accommodate certain groups of carers.

## Adult Day Service Centers Have Two Primary Goals:

1. To provide individuals with needed care, socialization, and supervision in a safe and comfortable community setting.
2. To provide carers respite from the demanding responsibilities of caring.

## Types of Adult Day Care

- 1. Social Day Centers** Focused on social activities, therapeutic recreation, meals, and some health care services. These may include medication monitoring and blood pressure checks. Staff also assist participants with daily activities such as toileting, walking, and eating.
- 2. Health Day Centers** Provide more intensive health, therapeutic, and social services for those with more complex medical problems. These centers also care for those who need rehabilitations following an accident or sickness, such as a broken hip or stroke. These services can include comprehensive nursing services and physical, speech, and occupational therapy as well as behavioral, counseling, and/or vocational rehabilitation services.



**3. Specialized Day Centers** Focused primarily on care and supervision for those with Alzheimer's disease or other types of dementia. This has been an area of primary focus in adult day services. These programs provide a safe and caring environment with purposeful activities specifically designed to benefit those with cognitive impairments.

### Why Do Family Carers Choose Adult Day Centers?

Adult day services provide carers with respite from the tiresome hours of caring. These centers are known for their reliability, overall quality of care, and their commitment to helping recipients as well as carers. Participants can usually attend full days, thus allowing family carers to remain in the workforce. Most centers provide support to carers through educational programs, support groups, and individual counseling.

### What Types of Services Do Adult Day Service Centers Offer?

Each center varies in the specific services listed as well as in the areas of expertise. Services may include:

- » **Transportation:** Door-to-door transportation assistance in a vehicle accessible to persons with disabilities, provided or arranged by the center staff.
- » **Social Activity:** Interaction with other participants in planned and entertaining activities.
- » **Meals and Snacks:** In addition, persons with special dietary and nutritional requirements are offered special meals. Those who have difficulty eating will receive assistance from the staff.
- » **Nursing Services:** Health-related care such as administering medications, blood pressure and diabetes monitoring, and monthly health check-ups.
- » **Personal Care:** Help with toileting, grooming, and other personal care activities.
- » **Counseling:** For assistance with depression and separation anxiety.
- » **Therapeutic Activities:** Exercise, skills training, and help with daily activities.
- » **Other Services for Family Carers:** Support groups, educational programs, etc.

### Adult Day Centers Care for Diverse Populations

Many adult day services are increasingly focusing on creating more disease-specific programs to help recipients diagnosed with chronic conditions and other diseases. Centers focus on health care and maintenance and offer physical education programs to help spread awareness about the prevention and treatment of diabetes, heart disease, obesity, and other health conditions.



Many recipients usually suffer from some form of dementia or Alzheimer's. Centers often offer cognitive stimulation programs, provide memory training programs, and offer more educational programs. These services fulfill many of the needs of the recipients and are beneficial to their overall health.

### **Adult Day Services Provide Comprehensive Skilled Health Care**

- » A full range of interdisciplinary professionals meet the physical, emotional, and social needs of participants and family carers.
- » Many adult day service centers have a nursing professional on staff, some a social worker, and many offer case management services.
- » Other professional services may include physical, occupational or speech therapy.
- » Ideally, there should be one care worker for every six participants, facilitating individualized, person-centered care and enabling staff to care for increasingly complex needs.
- » Adult day service centers serve as an emerging provider of transitional care, but also short-term rehabilitation following hospital discharge.

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# Technology and Carers

## Introduction

Advancements in technology have led to an era of the “cloud” in which almost everyone is connected to the Internet through their technological devices. The increasing availability and accessibility of Internet-based technologies and mobile devices has allowed aging adults and their carers to address a range of medical, health, social, and practical needs. Aging adults and carers rely on mobile devices to make their lives easier. At the same time, assistive technologies have grown in sophistication and many health providers are using robust IT systems to make electronic health records accessible to aging adults, people with disabilities, and family carers. Technology offers practical solutions for carers seeking to solve a problem, learn new skills and get quicker support. This fact sheet offers an introduction to some of the tools currently available to help carers and the people they care for manage their caring responsibilities and other tasks.

There are thousands of health-related applications (apps) available on the Apple and Android mobile platforms. With the overwhelming number of applications to choose from, it is important to find the right one for your needs or situation. Luckily, almost all of these apps are easy to use. There are no special credentials or qualifications required to download mobile applications from a website. Anyone with a computer or mobile device, and internet/Wi-Fi access can access information on the Internet. However, it is important to acknowledge that there is no guarantee that the app or website has credible information unless it is from a reliable source, or it lists references.

## Finding the Right Technology Tools

- » Search online to read or discover about the kinds of products you are interested in;
- » Look at customer reviews or professional recommendations for credible information;
- » Ask friends or relatives what websites or apps they recommend or use;
- » Ask an employee at a nearby electronics store to assist you in finding the product for a certain issue;
- » Call or talk to a family member, friend or customer service provider for technical assistance on a specific product. In some countries, like the UK, there are not-for-profit organizations which specialize in helping people understand what types of technology exist that might help them.

## Different Tools Are Available for Carers

**Environmental Sensors** are designed to provide carers peace of mind and alert them to potential safety problems. These sensors can detect motion of the care recipient, adjust lighting, alert to the presence of carbon monoxide or fire, and identify if the stove is on, as well as if the refrigerator has been used.

**Fall Prevention Technology** is available to detect falls and alert carers and emergency responders that the aging individual or a person with disabilities has fallen and needs assistance.

**Medication Optimization** consists of a variety of technologies intended to help manage medication information, dispensing, payments, medication schedule, and tracking. Medication dispensers can be purchased, which provides the correct dosage of medications. Other devices are available which provide reminders to the patient and alerts the caregiver if the medication has not been taken.

**Mobile Health** or mHealth is a fast-growing area of telehealth that seeks to improve care processes, expand access to care, and reduce the costs of care. MHealth is the delivery of health-related services to patients, clinicians and carers through mobile technology platforms. Often, mHealth services are delivered through mobile applications (or “apps”) available on tablets and smartphones through the Apple, Android, or Microsoft app stores. Mobile health services can contribute greatly to improved health for older adults in areas such as medication compliance, chronic disease monitoring, safety monitoring, access to health information, and communication with health and social service providers. There are even shoes currently on the market with the GPS tracking system that carers purchase for persons with dementia!

**Mobile Personal Emergency Response Systems (PERS) and Global Position Service (GPS)** are devices that can track an individual outside their home and alert the caregiver if the person wanders outside a defined area. These devices are sometimes connected to a piece of jewelry, or as a mobile app on the person’s phone.

**Technology-Enabled Post-Acute Transitional Care (PACT)** is designed to ensure the coordination and continuity of health care as patients transfer from hospital to home or similar settings. These transition interventions focus on improving the care transitions process, providing direct patient support, improving self-management capabilities, and increasing access to needed information and tools. Several types of technologies are being used to support post-acute care transitions (PACT) interventions.

**Remote Patient Monitoring** (RPM) refers to a large variety of technologies intended to manage and monitor a range of health conditions. Devices such as weight scales, glucometers, and blood pressure monitors provide alerts when health conditions decline. These technologies are useful for the elderly, chronically ill, and people who have trouble accessing traditional sites of care.

**Telecare** refers to technology that allows patients to stay safe and independent in their homes, through the use of telecommunications technology such as smartphones, computers, and tablets. Sometimes a physician, nurse, or other health care provider can use telecare or “telehealth” to conduct a remote visit and collect information about the older person. Telecare devices can be used as medical alarms, automatic gas shut-off devices, health monitoring, and home entry videophones. Telecare involves frequent remote monitoring of patients by carers, with the purpose of receiving warnings about real-time emergencies and tracking lifestyle changes over time.

### **Different types of technological devices to help carers**

Many carers have an internet connection and go online for business, searching information, connecting with friends, and for entertainment. With a larger percentage of people ageing and retiring, the use of technologies to manage their own care and the care of others will increase. Technology is generally viewed more positively as a regular part of daily life. Currently amongst older people, there is an increased demand for technological solutions to make their lives easier. Devices such as applications (apps), smartphones, tablets, laptops, and game consoles may all be utilized by carers to handle health care tasks or cope with stress.

### **Types of carer applications and websites**

There are thousands of health-related applications (apps) available on the Apple and Android mobile platforms. With the overwhelming number of applications to choose from, it is important to find the right one for your needs or situation. Luckily, almost all of these apps are easy to use. There are no special credentials or qualifications required to download mobile applications from a website. Anyone with a computer or mobile device, and internet/Wi-Fi access can access information on the Internet, especially if we keep in mind that there are also apps and websites accessible to blind persons and persons with vision impairments. However, it is important to acknowledge that there is no guarantee that the app or website has credible information unless it is from a reliable source or it lists references.

**Coordinating Care:** Carers can get help by posting information online for friends and family about life and care issues. Coordinating care can be a simpler process by discussing with others online. Many online tools allow a carer to post information or set up a calendar for others in the care circle to stay updated about someone they all care for. These tools can also be used to manage appointments and share tasks.

Carers UK has developed its own care tool – *Jointly* – to help relatives, friends and workers to manage care. Aging adults and people with disabilities are also using it to manage their own care. More information can be found at: <https://www.jointlyapp.com/#welcome>

**Entertainment:** While schedules are often very busy, carers can find time for entertainment through an array of applications available on mobile technology. Games, movies, television shows, and music can all help with stress management. Social media, such as Facebook and Twitter, may also offer carers with a way to connect with others who are engaged in caregiving. Many of these apps are free to download and can even be played with friends or family members.

**Exercise and Nutrition:** There are applications available that monitor your nutrition and your exercise, including indicators of health, such as daily steps. This can help a caregiver or the person they are caring for keep track of their health and set goals for better nutrition and improved activity. Other apps offer recipes for simple, healthy meals and recommend meals based on your dietary restrictions.

**Information and Education:** Carer information classes are offered in the form of a webinar through certain companies and organizations. Webinars are online seminars where people can listen to a live presenter on their computer or smartphone.

**Medication Management:** There are applications available that act as medication scheduling trackers and reminder alarms that can all be modified to fit someone's schedule. Some applications list which pills may be harmful or non-harmful when combined with other pills, such as taking aspirin and acetaminophen together.

**Meditation and Spirituality:** Sometimes a physical respite from caring is not always possible. You may find yourself with a mere 10-15 minutes to yourself on a particularly stressful day of caring—not long enough for a hot bath, perhaps, but enough time to calm your mind with an audio-based app playing nature sounds, soothing music or a repetition of mantras or chants. Whatever works to calm your mind can certainly work on calming your body.



**Personal Health Record Tracking:** Keeping track of all those doctors' appointments, hospital visits, insurance records, immunization dates, and other medical related topics can be a hassle and leave carers feeling disorganized. Several applications offer secure tools to organize these health records and keep track of possible symptoms or test results. In some cases, a health system or health care provider may offer a special app with access to the personal health record, appointment tracking, and secure messaging to the physician or other health professional.

**Safety:** Caring for the safety and well-being of another is a priority of a carer. With this in mind, carers can download applications that allow them to track and locate where someone is. This is beneficial to those who care for someone who is still traveling independently or lives alone. Tracking apps can also be helpful to those caring for someone with dementia, who may wander, by allowing them to find their family member quickly.

**Shopping for Goods and Services:** Caring responsibilities can be time-constraining for carers when they need to run errands. There are websites and applications available to manage finances, shopping, and even groceries. These can help carers save time and prevent multiple trips to the bank and stores.

**Social and Emotional Support:** Carers can talk to other carers or carer counselors by phone or online if they feel alone, isolated, stressed out, or depressed. Some websites and apps offer message boards or forums which give carers a space for virtual support groups. Other carers may get involved in advocacy on Facebook and Twitter, where they can share articles, petitions, and information about caregiving in their localities or nations.

## Conclusion

As a reminder, certain technology can be expensive. It can be less expensive than an assisted living facility or a nursing home, but a carer must weigh the pros and cons of keeping the aging adult in their home versus nurse/paid carer assistance. Technology is an excellent tool to be utilized, but carers must understand that it is not to be the predominant method for off-site or long-distance caring.

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# End of Life Issues Faced by Carers

## Introduction

For many family carers, caregiving responsibilities end as a result of the death of the care recipient. Preparing in advance for the simultaneous end of life and end of caregiving is a strategy that can support both the carer and the care recipient. However, there are several barriers to managing this preparation, including:

- » **The difficulty of having an open and frank discussion between carer and care recipient about death;**
- » **Reticence on the part of the carer or the care recipient to even broach the topic of death;**
- » **A lack of awareness of existing tools and strategies for advanced care planning;**
- » **Misunderstanding about where death occurs and how it can be proactively managed.**

This fact sheet will review some tools and strategies that are available to support end of life conversations and planning for the benefit of both caregivers and those they are helping.

## Hospice versus Palliative Care

### Hospice Care

Hospice care is provided in a hospice facility or at home. In most instances, hospice care is provided at home after a health care provider has determined that the patient has fewer than six months to live. This care is often covered under the care recipient's insurance and is provided by trained hospice health professionals. During hospice care, interventions to prolong life are not offered to the patient. Hospice care was first developed in the United Kingdom and is widely available internationally.

### Palliative Care

Palliative care, also referred to as comfort care, is a type of care that seeks to minimize the pain and suffering an individual may experience during the end of their life or at

other times when serious illness is present. Palliative care can be provided in the home, in a hospice or a health care setting, such as a hospital. Palliative care can be provided at any time and is not based upon a diagnosis of death within six months. There are no time limits to palliative care; the care is available when needed or for however long this care is required. Since it is not hospice care, it is not necessary to avoid interventions designed to prolong life.

### Planning for the End

Although it is difficult to have an open and frank discussion about death, care recipients who share their feelings and preferences about the end of life choices are giving an important gift to the carer who, at some point, will be faced with making decisions about the last moments of their life. Technological changes make it possible for people nearing death to remain alive when there is no quality of life or hope for the future. Futile efforts to sustain life are not only costly but create difficult situations for the family and patient. Advanced care plans provide key strategies for making our wishes known and giving carers the information they need to make decisions that are respectful of the person being cared for. All states in the US have care-at-the-end-of-life forms to complete and most countries have provisions for advanced care planning. These *advance directives* serve as a tool to indicate the individual's preferences about aid in dying, death with dignity and *do not resuscitate* choices for use if the individual is unable to communicate these preferences directly.

The act of completing an "advance directive" can inform the carer about preferences for the end, which can clarify the uncertainty about individual preferences if the care recipient is unable to communicate them. Even if an advance directive is not available, health professionals providing care for the individual will ask a caregiver about these choices. Knowing what the care recipient wants provides the carer with confidence about making the decisions, if needed. Therefore, it is important to have the conversation early in the caregiving process. Although most people report that they would prefer to die in their home, in the United States, almost half (45%) of terminally ill patients die in hospital settings.

Preparing for the end will benefit both the carer and the care recipient. In the United Kingdom, the "gold standard framework," developed by a physician, has a goal of respecting the patient's preferences, developing a plan for care and focusing on care in the home rather than the hospital. The framework values coordination of care in order that needed care is seamless and of high quality. It also includes a goal of ensuring that care professionals are educated and trained in order to provide the highest quality of care possible.

End of life is an emotionally sensitive time for the ill person who has only a short time to live, but it is also highly sensitive for the carer, as well as the care team providing needed services to the patient and support to the caregiver(s). Preparing for this transition by seeking professional help and consultation with the purpose of understanding the process and the options for care and support of the loved one, will make it easier on caregivers and patients. Professional care providers in a hospice, hospital or the community can provide information and support the patient's decisions in advance of the dying process.

For more information about how you can support the person you love during this difficult process, you can ask your health care provider to give you educational material that will help you prepare and make plans.

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We hope that you have found this Toolkit useful. Please contact us with any questions. We welcome your feedback and suggestions for materials which we hope to develop in the future. They will be incorporated into the online version of the Toolkit, which can be accessed at [www.internationalcarers.org](http://www.internationalcarers.org)

Comments and questions can be submitted to the IACO team at [www.internationalcarers.org/contact](http://www.internationalcarers.org/contact)

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