2017 Carers Report

Embracing the Critical Role of Caregivers Around the World

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in association with:

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Introduction

Every day, in every community around the world, people provide care for those who need it most, often putting their own lives on hold or altering their daily routines to ensure that an ill or disabled loved one or friend has the support they need. Known as caregivers, these individuals often get little support or recognition for the work they do, but they are essential for improving patient outcomes. Caregivers are not limited by culture or country, they are universal—sharing common traits and facing common challenges.

Who is a caregiver? He or she is usually an unpaid family member or friend who provides care to a person who, due to an illness, disability, or mental health issue, cannot cope without support. Some people assume caregiver responsibilities gradually, following the diagnosis of an illness that progresses slowly, such as Alzheimer’s disease. Others are thrust into the caregiver role seconds after a loved one’s accident or catastrophic illness. Their lives are lastingly affected and a new relationship emerges between the person in need of care and his or her caregiver.

While there are emotional rewards in caring for a loved one, friend, or someone in need, many caregivers soon find that they themselves are in need of support. The logistics of pursuing a professional or academic life while being a caregiver can lead to problems such as absenteeism and workday interruptions. These and other care-related stress factors can have an impact on caregivers’ health and well-being, affect important relationships in their lives and even result in financial pressures.

Because caring for a loved one in need is such a natural part of life, the needs of caregivers as a group have gone largely unnoticed and unsupported by society. Fortunately, there are a range of local, national, and international organizations providing caregiver support.
Additionally, there are organizations bringing together these great resources across the world to enhance and augment activities. For example, the Eurocarers\(^1\) network, established in 2006, currently brings together 67 caregivers’ organizations, as well as relevant research, and development organizations from 25 countries – a unique combination that enables evidence-based advocacy. Eurocarers works for a future in which caring is recognized and valued, and in which unpaid caregivers do not face poverty, social exclusion, or discrimination.

The International Alliance of Carer Organizations (IACO)\(^2\) was started as an umbrella organization in 2012, joining caregivers’ organizations across the world to provide cohesive direction for research, education, and awareness efforts, and to facilitate information sharing, and advocate for caregivers at an international level. More recently, the World Health Organization (WHO) has recognized the critical importance of caregivers within their Framework on Integrated People-Centered Health Services and released a Global Action Plan for caregivers of people with dementia.\(^3\) Today many organizations around the globe are providing information, services, and advocacy in support of the caregiver community.

“There are four kinds of people in the world: Those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.”

— Rosalynn Carter, Former First Lady of the United States of America
Portrait of a Caregiver

Caregivers can be any age, come from any socioeconomic group, and live anywhere in the world. They help with everyday activities such as dressing, cooking, eating, using the bathroom/toileting activities, taking medication, and going to the doctor. They also help with the simple tasks most of us take for granted, like getting into bed or getting out of a chair. Some also provide technical home care such as dialysis, use of suction machine, incontinence management, catheter care, physiotherapy and speech therapy, chiropody, peg feeding, etc.
In the US, it is estimated that there are 65.7 million unpaid family caregivers providing care to someone who is ill, disabled, or aged.\textsuperscript{4} Data derived from the European Quality of Life Survey estimates that there are about 100 million caregivers in Europe today, 20 percent of the EU population. In the UK, the number of caregivers stands at 6.5 million;\textsuperscript{5} while in Australia, there are approximately 2.7 million unpaid caregivers.\textsuperscript{6}

Caregivers provide a vast array of emotional, financial, nursing, social, homemaking, and other services on a daily or intermittent basis. While the monetary value of caregivers is difficult to quantify, more outpatient care and fewer hospital stays all contribute to the AUD60.3 billion estimated annual value of caregivers’ contributions in Australia alone. That amounts to more than AUD1 billion per week.\textsuperscript{7} Estimates also suggest that the economic value of unpaid care, as a percentage of the overall cost of formal long-term care provision in EU Member States, ranges from 50 percent to 90 percent. For example, in the UK, it has been calculated that the value of unpaid care is now worth a staggering £132 billion—a huge contribution in times of austerity, as well as tight health and social care budgets.\textsuperscript{8}

Caring for a loved one is an activity that cuts across most demographic groups regardless of age, race, educational attainment, and household income, but is especially prevalent among women and adults aged 30 to 64, a group traditionally still in the workforce.\textsuperscript{9} In the UK, on average 58 percent of 50-65-year-olds who provide assistance to a parent are women.\textsuperscript{10} In India and Nepal, 84 percent of caregivers are women, and a recent study found approximately 96 percent of the caregivers are of working age.\textsuperscript{11} Some differences have been reported in caregiving among different ethnic groups. For example, in the US, Hispanic caregivers are typically younger than Caucasian caregivers, and Asian caregivers are equally likely to be male or female.\textsuperscript{12}
Common Characteristics of Caregivers

In the UK, 58 percent of caregivers are female and 42 percent are male.\textsuperscript{13}

In the EU, a typical caregiver is a woman between 45 and 75 years of age.\textsuperscript{14} In Australia, females make up the majority of caregivers, representing 68.1 percent of primary caregivers and 55.5 percent of all caregivers.\textsuperscript{15}

In the US, 72 percent of caregivers are online health seekers, compared with 50 percent of non-caregivers.\textsuperscript{16}

In Australia, the weekly median income of primary caregivers aged 15-64 was 42 percent lower than that of non-caregivers.\textsuperscript{17}

In the EU, 42 percent of non-working caregivers are in the lowest income quartile.\textsuperscript{18}

In the US, caregivers of people with Alzheimer’s disease and other dementias provide care for a longer time, on average, than caregivers of older adults with other conditions.\textsuperscript{19}

Caregivers in the UK state that caring had a negative impact on their physical (83 percent) and mental (87 percent) health.\textsuperscript{20} And approximately 28 percent of UK caregivers stated that they had their own physical disability.\textsuperscript{21}
The Embracing Carers™ Initiative

Merck KGaA, Darmstadt, Germany, a leading science and technology company in healthcare, life science, and performance materials, guided by caregiving organizations that act as global strategic advisors, has launched a global initiative to seek opportunities to recognize the important role of caregivers in society and provide support for caregivers worldwide. The Embracing Carers™ Initiative is a new global platform and movement dedicated to empowering caregivers and helping them put greater focus on their own health and well-being, bringing greater balance to their lives. Its mission is to increase global recognition of the unmet challenges of caregivers and the practical solutions to support them; drive policy-focused, legislative action, and visibility among policy makers, governments, and international public health organizations; and create innovative opportunities to integrate caregiver support and resources through the healthcare system.

Globally, caregivers are facing many of the same challenges regardless of age, employment status, or gender. Understanding these challenges is critical to identifying the actions to be taken to increase recognition and support for the larger caregiver community. One of the first steps for the Embracing Carers™ Initiative was to identify key issues and trends through fact-finding activities and an international caregiver survey designed to better understand the emotional state and needs of caregivers, and identify challenges and opportunities that can be addressed through this collaborative effort. The initiative recognizes the importance—to society, to employers, to educators, to the health community, to families, to caregivers, and to those they care for—of working with a broad spectrum of stakeholders worldwide to take action that improves support and services for caregivers.
Embracing Carers™ Strategic Advisors

Caregiver Action Network serves a broad spectrum of family caregivers ranging from the parents of children with special needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer’s disease. CAN (the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the US free of charge.

Carers Australia is the national peak body representing Australia’s carers, advocating on behalf of Australia’s carers to influence policies and services at a national level. It works collaboratively with partners and its member organizations, the Network of state and territory Carers Associations, to deliver a range of essential national carer services.

Established in 1965, Carers UK is the UK’s only national membership charity for carers, offering a supportive community and leading a movement for change. Its mission is to make life better for carers, through giving expert advice, information and support; connecting carers so no one has to care alone; campaigning together for lasting change; and innovating to find new ways to reach and support carers.

Carers Worldwide develops and promotes cost effective, sustainable and easily replicable methods of providing support to carers in low and middle income countries. It aims to enable service providers, policy makers and other stakeholders to recognize and respond to the needs of carers in the developing world, ensuring balance and equal value is given to the needs of the carer and the person receiving care. Carers Worldwide currently has programs in India, Nepal and Bangladesh.
**Eurocarers** is a European network representing informal carers and their organizations, seeking to advance the recognition of informal care acting on behalf of all carers, former carers, and their organizations, irrespective of their age or the particular health need of the person they caring for. Eurocarers brings together carers’ organizations as well as relevant universities and research institutes to ensure that care is valued and unpaid care is recognized as central to the sustainability of health and long term care systems.

Established in 1996, the **National Alliance for Caregiving** is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy in the US. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.

Incorporated in 2012, the **International Alliance of Carer Organizations (IACO)** serves as an umbrella organization that provides cohesive direction, facilitates information sharing, and actively advocates for carers at an international level. IACO aims to investigate and address issues of international family caregiving with the intent of increasing public awareness of the needs of the family caregiver on a global scale.

The Shanghai branch of **Roots & Shoots** was founded as a volunteer organization in November, 1999. Five years later, in November, 2004, Roots & Shoots was granted a Non-Profit Organization status by the Shanghai Municipality Government. The program aims to foster respect and compassion for all living things, to promote understanding of all cultures and beliefs, and to empower and inspire individuals to take action to make a positive difference in our world.
Global Carer Survey

An online survey conducted by Censuswide on behalf of Merck KGaA, Darmstadt, Germany questioned 3,516 unpaid caregivers aged 18-75—across Australia, France, Germany, Italy, Spain, the UK and the US—to assess key information directly from them. After gathering some basic demographic data, the questionnaire was designed to identify the respondent’s situation and understand the impact caring has had on his/her life, looking at the impact on health, finances, employment, and emotional state. The survey focused on several key areas of an unpaid caregiver’s life.

Employment Survey Findings:

One of the greatest challenges for unpaid caregivers is trying to balance employment, personal life, and the additional caregiver responsibilities.

- More than 1 in 5 (21 percent) of unpaid caregivers feel their careers have been negatively affected by their role as an unpaid caregiver.
- Approximately 12 percent of unpaid caregivers had to give up their job because of their role as a caregiver.
- 18 percent of unpaid caregivers in Australia had to give up their job because of their role as an unpaid caregiver. This compares to 7 percent in Germany and 8 percent in Italy.
- More than 1 in 5 (21 percent) of unpaid caregivers had to reduce the number of hours they work to care for a family member.

As highlighted by the survey, many unpaid caregivers say their work has been negatively impacted by becoming a caregiver. In addition, they say employers do not have policies in place to support them, including policies that would allow them to reduce their hours, establish flextime to accommodate their changing schedules, work from home, or workshare with another employee. These statistics mesh well with a survey orchestrated by the Australian Bureau of Statistics in 2015, which showed that for people aged 15-64, the labor force participation rate for primary caregivers (56.3 percent) and other caregivers (77.2 percent) was lower than for non–caregivers (80.3 percent).²²
A critical group of unpaid caregivers are the “sandwich caregivers” or middle-aged caregivers who simultaneously take care of elderly relatives while taking care of their children. The role of sandwich caregivers remains a responsibility largely undertaken by women in most parts of the world. A considerable number of American women find themselves employed full-time in addition to caregiving 20 hours a week—the equivalent of a second part-time job.23

The majority of adult caregivers in the US are female,24 and this figure rises to around 66 percent in Australia.25 In the EU, it is mostly women who give up paid jobs or reduce working hours in order to fulfill caregiver responsibilities.26 For female sandwich caregivers, the impact on employment status is significant. A recent Eurofound survey discovered that among those with caring responsibilities, 90 percent of men work full-time, whereas only 50 percent of women are able to work full-time.27 Many women spend a large part of their lives caring for children and adult family members while simultaneously working outside of the home.28

Employers also experience missed productivity, which costs millions of dollars each year. Missed deadlines and the frequent need for time off often create friction between employees and employers. In the US, approximately two percent of caregivers quit working each year to devote more time to being a caregiver, which costs companies approximately $2.8 billion a year to replace the employees who left.29 In the UK, approximately £5.3 billion has been lost due to people dropping out of the workforce to take on caring responsibilities for older or disabled loved ones.30 In the EU, it has been calculated that the total value of unpaid care could range between 20.1 percent and 36.8 percent of the GDP.31

Types of costs to employers include:

- Absenteeism
- Arriving late and/or leaving early
- Workday interruptions
- Unpaid leave
- Reduced hours
- Employee turnover
- Recruitment for empty positions
Financial Impact Survey Findings:
Caring for someone in need can often create or exacerbate financial problems.

- 30 percent of unpaid caregivers now have increased financial pressures as a result of their role as an unpaid caregiver.
- 12 percent of unpaid caregivers had to give up their job because of their role as an unpaid caregiver.
- A third (33 percent) of female unpaid caregivers and a quarter (25 percent) of male unpaid caregivers feel being a caregiver has put pressure on their financial situation.
- Approximately 37 percent of unpaid caregivers aged 56-65 feel being an unpaid caregiver has put pressure on their financial situation.

As underscored by the survey, many caregivers on tight budgets face financial obstacles; not having enough money to buy food, clothing, or even medicine, aids and adaptations that the person they are caring for require. Additional costs include caregivers using unpaid time off, reducing their work hours or quitting their jobs to stay home and care for their loved ones. In most countries, few programs exist to provide financial aid for caregivers.

“An aging population means that caring for older or disabled loved ones is inevitable for all families. Workplace and care services must catch up with this reality of family life.”

Heléna Herklots, CEO, Carers UK
Caregiver Support Survey Findings:

Unpaid caregivers spend countless hours with the people they care for, sometimes with little support from others, despite being a critical component of their community and society.

- **Almost 3 in 10 (28 percent)** of unpaid caregivers feel their role as a caregiver is unrecognized by their healthcare system.

- **Approximately 43 percent** of unpaid caregivers who live in suburban areas do not feel supported at all in their role as an unpaid caregiver by social/welfare services.

- In Germany, **4 in 5 (80 percent)** unpaid caregivers feel supported in their role as a caregiver by their health insurance provider, compared to 32 percent in the UK.

- In the UK, **7 in 10 (70 percent)** of unpaid caregivers do not feel supported at all by their religious institution or faith community, compared to 40 percent in the US.

- **57 percent** of female unpaid caregivers do not feel supported at all in their role as an unpaid caregiver by the government.

The majority of caregivers do not feel their role of supporting patients is understood and valued by their community, which encompasses friends, neighbors, local shops, their healthcare system, social services, and local government agencies. While some caregivers choose not to share much information about their situation with their neighbors, in many cases, the local community is simply not equipped to understand the level of work and stress that caregivers are under as they support their loved ones. Some caregivers have said that when they do seek help from their community, it can sometimes be very challenging because of an overall lack of knowledge about the pivotal role of the caregiver in patient care. Caregivers who struggle with unsupportive communities were more likely to never or rarely be able to balance or maintain other areas of their lives alongside caring.
In many countries, little in the way of state or national government policy and nationally coordinated support are designed to ease the challenges experienced by caregivers. Legislation is needed for caregivers that is much like the legislation created to help young families balance work and family obligations. To address the challenges of young families, many countries crafted public policies that support paid leave for new parents, flexible scheduling, paid sick days that can be used for family care, and prohibitions on workplace discrimination based on family responsibilities. This same level of legislation is also needed to support caregivers.

Healthcare Support Survey Findings:
Supporting the health and well-being of someone else is an unpaid caregiver’s top priority, but at what expense? Around the world unpaid caregivers are neglecting their own health in order to care for others.

- More than half (54 percent) of unpaid caregivers don’t have time to book or attend their own medical appointments.
- More than half (55 percent) feel that their physical health has suffered.
- About 42 percent of unpaid caregivers put the health of the person they are caring for above themselves.
- Nearly half (47 percent) of unpaid caregivers have feelings of depression with almost 3 in 5 (57 percent) feeling that they needed medical care/support for a mental health condition (e.g., depression, anxiety, stress) due to their role as caregiver. Of these, a quarter (25 percent) have not sought medical help.
- More than a third (37 percent) of French unpaid caregivers have increased their intake of prescription drugs or painkillers.
- Almost a quarter (23 percent) of unpaid caregivers have become dependent on alcohol and/or smoking each day.

Some health issues that may affect caregivers:
- Lack of exercise
- Difficulty sleeping
- Weight gain/loss
- Alcohol/smoking dependence
- Cut corners on personal health checks
- Depression
This survey and other studies show that while caregivers are dedicated to improving the health of those they care for, they often neglect their own health. Caregivers have identified the main barriers to maintaining their health, including lack of time to exercise and difficulty sleeping. Many said they have experienced worsening mental health issues and that they have let a physical health problem go untreated. Some caregivers only seek medical help when they experience an emergency. The emotional and physical stress of caring can be overwhelming to many caregivers. According to results from the 3rd European Quality of Life Survey, 14 percent of non-working caregivers say they are depressed all or most of the time, more than twice as high as the corresponding figure for working caregivers. That report seems to indicate that the worst situation for a caregiver is not the stress of juggling the responsibilities of work and care, it’s the stress of not being able to work.\textsuperscript{34}

One factor that adds to caregiver health issues is that caregivers seldom get any training or information about the importance of caring for their own health while they care for other people. As reported by the Building Carer Friendly Communities Research Report for Carers Week 2016, the role that health and care services have in helping caregivers maintain their own health is paramount. Caregivers need support from their physicians and care services to help them look after their own health. They also need the knowledge, training, and skills to care safely and well, so that they can stay healthy and continue in their valuable role as a caregiver.\textsuperscript{35}

**Young Caregiver:** There are a considerable number of young caregivers supporting sick or disabled siblings, parents, or elderly relatives.

- **More than a quarter of unpaid caregivers (26 percent)** aged 18-25 are caring for a person aged 18-35.

- **More than 1 in 5 (21 percent)** unpaid caregivers aged 18-25 are caring for a person aged 51-64.

- Younger caregivers are more likely to agree that they often don’t have time to book or attend medical appointments for themselves, with **58 percent of caregivers aged 18-25** agreeing that they don’t, compared to just **24 percent** of those aged 66-75.
In the US, it is estimated that there are approximately 1.4 million young caregivers aged 8-18. As to be expected, this burden has a detrimental impact on these young caregivers’ education and their childhood; instead of learning at school and playing with friends, they shop for food, prepare meals, clean the house, take care of younger siblings, and generally help the family member in need.

The missed educational opportunities of caregivers is an issue on two fronts: 1) younger caregivers who sacrifice their educations and possible future employment opportunities by taking time off from their studies; and 2) middle-aged workforce caregivers who are returning to education to reskill or advance their careers. Many of these caregivers say their places of education have few, if any, policies in place to support them in their studies as they struggle to balance school with caring. Many student caregivers reported a lack of flexibility in timetables or deadlines, and some said they are unable to advance their education. Others have given up their studies altogether and now worry about their future employment prospects.

**Older Caregivers:** Older caregivers are more likely to co-care (care for each other) than other groups and often have health issues of their own that require care and support. The rising number of people who are elderly is contributing to the need for a rising number of caregivers.

- More than half of unpaid caregivers (51 percent) aged 66-75 are caring for a person with a physical disability.
- Approximately 16 percent of unpaid caregivers aged 66-75 are caring for a person with cancer. This compares to 8 percent of unpaid caregivers aged 18-25.
- More than half of unpaid caregivers (51 percent) are caring for a person aged 65 and over.
- A third of unpaid caregivers (33 percent) in the UK are caring for a person aged 65 and over, this compares to more than two thirds (67 percent) in Italy.

*With an aging population, becoming a carer-friendly workplace makes business sense. Providing flexible and supportive working conditions to enable employees to combine paid work with an unpaid caring role will ensure employers are able to hold onto experienced workers.*

_Ara Cresswell, CEO, Carers Australia_
In Germany in 2015, the population age 60 and older was 27.6%. By 2030, it is expected to increase to 36.1%. In the US, one in eight Americans is 65 or older, and these numbers will double between 2000 and 2030. Nearly one in four aged 60 or over in the world in 2015 lived in China. In fact, the five countries with the largest number of oldest-old persons—the US, China, India, Japan and Germany—collectively accounted for 48 percent of the world’s oldest-old in 2015. Increasing age and declining health also impact older caregivers’ ability to maintain a healthy lifestyle while caring for others. This cycle of caregivers experiencing declining health and potentially requiring caregivers themselves will result in greater demands for resources and assistance.
Building on Successful Solutions

Fortunately, many organizations around the globe—grassroots, nongovernmental, governmental, healthcare, educational, and corporate— are working to address the unmet needs of caregivers by identifying the challenges that must be addressed, finding practical solutions to improve caregivers health and well-being, and taking action. While many of the organizations committed to the global Embracing Carers™ Initiative have a variety of programs that apply to several of the issues outlined below, there are a few specific examples that highlight best practices and should be emulated and replicated around the world.

**Employee/Employer:** Since employment is one of biggest problems that affects both caregivers and employers, many companies have introduced practical measures to identify and support employees with caregiver responsibilities. Forbes magazine underscored this movement in their blog *Next Avenue* called “A New Era: Companies Supporting Caregivers,” which cited examples of several companies, including some Fortune 500 companies, that provide caregiver programs to their employees.42

One such Fortune 500 company, British Telecommunications (BT), a communications services company operating in more than 170 countries and employing more than 100,000 workers, respects their employees’ desire to perform well at work, and meet their personal responsibilities, such as unpaid caring.43 The company issued a policy statement that recognizes the commitment borne by employees with unpaid care responsibilities, and implemented a program called “Helping You Care,” which outlines their approach to caregivers along with a wide-ranging toolkit of support already in place for working caregivers.
Many other companies are following suit; in fact, the European Foundation for the Improvement of Living and Working Conditions created a database that highlights some 50 company initiatives that support workers with dependent-care responsibilities in 10 member states.\textsuperscript{44} In addition, several of the Embracing Carers\textsuperscript{TM} strategic advisors have also put policies and programs in place to address this issue. Groups like Eurocarers, Carers Australia, Carers UK and Caregiver Action Network (CAN), to name a few, have published policy papers and created valuable resources to help companies become more caregiver-friendly workplaces.\textsuperscript{45} They also have developed useful resources for the family caregiver who is also working.

**Recognition:** All groups in the Embracing Carers\textsuperscript{TM} Initiative, along with many patient organizations around the world, are working to bring greater recognition to the value that caregivers bring to society and the need to support them through a variety of efforts. For instance, Carers Week, a collaboration with Carers UK and other organizations, has published a research report called “Building Carer Friendly Communities” to highlight the need for support and understanding of caregivers from their community by focusing on how communities can support caregivers to live well.\textsuperscript{46}

Carers Worldwide,\textsuperscript{47} which acts as a catalyst to equip local organizations to provide support to caregivers in low- and middle-income countries, seeks to enable caregivers, service providers, policy makers, and other stakeholders to recognize and respond to the needs of caregivers in the developing world, ensuring balance and equal value is given to the needs of the caregiver and the person receiving care. Building on these types of programs at the grassroots, as well as national, and international level will elevate the recognition of caregivers as a great resource for our society as a whole.

“Carers are invisible. They are hidden behind the curtain. They are among us, but we don’t have the eyes to see them.”

Anil Patil, Executive Director, Carers Worldwide
**Policies:** Recognizing that big changes can only happen if governmental policies are implemented to aid in the recognition and support of caregivers, some organizations are deeply involved with their respective governments to help bring about policy changes. For instance, Eurocarers[^48] is working to ensure that EU and national policies consider caregivers’ concerns and promote their inclusion, to develop support services, and to enable caregivers to remain active in paid employment and maintain a social life. In fact, they are calling for the development of an ambitious and comprehensive EU-level initiative that would address the various challenges facing caregivers throughout Europe by encouraging member states to recognize and support their significant contribution to care systems and society as a whole.

“As unpaid carers are vital providers of care services, it is important to watch for the system being exploitative of them. Policy makers and care system actors should be made aware of the adverse effect of unsupported unpaid care on carers themselves, as it raises their risk of falling through the safety net. To counteract this, family members should be empowered to take care of their loved ones - if they wish to do so – while receiving adequate support from the formalized care system.”

— Stecy Yghemonos, Executive Director, Eurocarers

In a similar fashion, Carers Australia[^49], the national leading body representing Australia’s caregivers, is advocating on behalf of Australia’s caregivers to influence policies and services at a national level. It works collaboratively with partners, and its member organizations, the network of state and territory caregivers associations, to deliver a range of essential national care services. In fact, in Australia there is legislation at the national and state territory level that recognizes the rights of caregivers. This legislation underpins government strategies and policies aimed at making life easier for caregivers. The same is true in the UK, where Carers UK[^50] has taken the lead in campaigning with and on behalf of caregivers for over 50 years, achieving significant legislative and policy gains.
In the US, there are several current legislative efforts regarding caregivers. Representative Michelle Lujan Grisham, a Democrat from New Mexico, and Representative Ileana Ros-Lehtinen, a Republican from Florida, have introduced the Care Corps Demonstration Act of 2017 (H.R. 3493) that would create a demonstration program designed to provide support for family caregivers and help meet the growing demand for the care of aging and disabled Americans. Representative Lujan Grisham has also introduced the National Corps Act of 2017 (H.R. 3494) to establish a National Care Corps, and to authorize grants for local care corps programs, through which qualified volunteers would provide care, companionship, and other services to individuals in need.

On an international level, the IACO provides research, awareness and education regarding family caregivers on a global scale. By bringing visibility and an understanding of the growing number of caregivers worldwide, IACO facilitates international collaboration by bringing together countries from around the globe that advocate for family caregivers. In most low- and middle-income countries, there is no government recognition or support for caregivers at the policy level and Carers Worldwide works systemically to address this in South Asia. Following in their footsteps, other governments and advocacy groups should build on these success stories.

**Caregiver Health:** Concerned that caregivers’ own mental and physical health is often neglected, some advocacy groups have created programs to address caregivers’ health needs. For instance, the National Alliance for Caregiving has a list of helpful reports that identify the challenges facing caregivers on career, finances, health, and potential solutions to address some of these challenges. One report in particular, completed in collaboration with Evercare and titled “Caregivers in Decline: A Close-up Look at the Health Risks of Caring for a Loved One,” highlights that the degree of deterioration in caregivers’ health increases in relation to the amount of time they spend caregiving and the intensity of their caregiving. The report goes on to offer several ideas on how to improve caregivers’ health.
Young Caregivers: Recognizing that young caregivers have a difficult time supporting themselves while caring for a loved one, and that taking time off from studies can affect their education and future employment opportunities, some organizations and universities have stepped in to help these students with financial aid and other programs. Groups such as Roots & Shoots provide educators with real tools that develop students’ 21st century learning skills, such as critical thinking, problem solving, and a spirit of collaboration. These tools include a free, online professional development course, toolkits, lesson plans, and $200 mini-grants to start and support their service campaigns. In India and Nepal, Carers Worldwide and its partners work with local educators to reintegrate young caregivers into school and to establish networks of peer support for those young people with care responsibilities in the home.

Government organizations and universities are also realizing the issues facing students who are also caregivers, and are implementing programs to help alleviate some of the stress that these young people are under. For instance, Carers Australia has dedicated a website to young caregivers, which facilitates information and applications to a bursary program funded by the Department of Social Services to give financial aid to young caregivers pursuing an education. In the US, the University of Michigan has support groups and websites to help student caregivers navigate their full lives, while the University of Cincinnati, Ohio has a resource guide to help student caregivers get through school a little easier. There is a need to build on these successful student support programs.
**Older Caregivers:** Older caregivers are more likely to co-care than other groups and have health issues of their own that require care and support. A 2015 New York Times article titled “More Caregivers Are No Spring Chickens Themselves” highlights the growing age of caregivers who assist siblings and other relatives, friends, or neighbors, most also 75 or older.

The Elders for Elders Foundation, an independent nonprofit foundation for the welfare of the aged in southern India, recently conducted a pilot project with Carers Worldwide highlighting the significant exclusion of caregivers of elders and of older caregivers themselves. Tailored programs of support can now be developed for this marginalized group. In the UK, Age UK Dacorum offers support to people who give unpaid care to a relative, neighbor, or friend, if one of them is over 50. Their aim is to help caregivers take control of their lives and situation so they can make decisions that are right for them. Building on successful programs that address the unique issues facing elderly caregivers is instrumental to enhancing the health and well-being of these people.

“Caregiver Action Network recognizes the many challenges caregivers face and has developed specific tools in Our Family Caregiver Toolbox to help address these challenges. The Toolbox features resources ranging from nutrition to depression and provides checklists, videos and support group information.”

— Lisa Winstel, Chief Operating Officer, Caregiver Action Network
Sandwich Caregiver: Sandwich caregivers are arguably the most time-deprived of all since they have to balance working full- or part-time with caring for an ill, injured, or older person and for a child, or children with a disability. Sandwich caregivers are also the most recognized of all the caregivers subgroups, as news organizations in the United Kingdom, Australia, and the US have been reporting on them. In fact, the *Sydney Morning Herald* recently reported that 1.5 million middle-aged Australians are sandwiched between caring for parents and children. In the UK the figure is 2.4 million\(^{59}\), and a 2015 article in *Time/Health*\(^ {60}\) citing the National Alliance for Caregiving, reports that almost one-third of Americans are caregivers and, of those, roughly 66 percent are females caring for children at home. As a result, several of the collaborative organizations have programs in place to address these types of caregivers. For instance, Eurocarers\(^ {61}\) cites a report based on 65 studies, including literature from EU member states, the US, and Australia, about reconciling care and work, especially for sandwich caregivers.

“Caring for family is a core part of the Chinese culture. But like many countries around the world, an aging population with adult children working full-time jobs, support and care of parents and grandparents can be challenging. China is taking a comprehensive approach to addressing elderly care and the growing needs of carers through the government’s 5-year plans by not only extending elderly healthcare services, but also through training and support for carers. Steps like these are critical to supporting the growing needs and demands on carers throughout China.”

— *Shanghai Roots & Shoots*
Embracing Carers™ is supported by Merck KGaA, Darmstadt, Germany, which operates its businesses as EMD Serono, MilliporeSigma and EMD Performance Materials in the US and Canada.
CALL TO ACTION

Greater understanding of the issues facing caregivers needs to translate into action. It is time to actively address and support caregivers in an unprecedented way. Only through working with the global community of caregiver organizations, patient groups, governments, employers, industry, and other key stakeholders, will caregivers around the world receive the recognition and support they so greatly need and deserve.

The Embracing Carers™ Initiative not only recognizes the need to shine a spotlight on the challenges caregivers face every day, but also strives to be part of the solution. As such, four key areas of action have been identified.
Broden Stakeholder Engagement | Through the tremendous work of many caregiver and patient organizations, great progress has been made. By building on these successes and recognizing the need to address further unmet needs, much more can be accomplished.

- Support capacity building and collaboration of caregiver organizations and among patient organizations to support caregiver initiatives.
- Engage with a broader sphere of stakeholders to elevate caregiver needs, promote collaboration and activate support programs.
- Extend the reach and involvement of employers, educators, and community groups to support the development of caregiver programs and initiatives.

Increase Global Awareness | Media attention of caregivers has been on the rise, and yet caregivers and their challenges continue to go largely unnoticed.

- Increase global discussion and bring to the forefront the unmet challenges of caregivers and practical solutions to support them.
- Support the caregiver community to drive awareness activities around the world.
- Activate and leverage the digital community to link the caregiver community, and drive greater awareness among the public, healthcare systems, and policy makers.

Activate Policy | Drive policy focus, legislative action and visibility among policy makers, governments, and international public health organizations.

- Share and promote best policy practices between countries, legislative bodies, and policy makers.
- Establish caregivers around the world as a recognized population within each country.
- Identify existing policy programs that can integrate and align caregiver-specific initiatives.

Engage Healthcare Systems | Create innovative opportunities to integrate caregiver support and resources throughout the spectrum of care.

- Evaluate best practices across key medical systems.
- Develop and share practical resources for the broader healthcare community to recognize caregiver needs, intervene, and link to meaningful support and solutions.
- Create greater links between healthcare systems and caregiver organizations and support services.
References


51 Carers Worldwide. (April 2016) An invisible workforce: understanding the issues and the needs of family carers in India. Page 8. No link. [Date Accessed: 7 September 2017]


