

 **Global Coalition on Aging**

**RELATIONSHIP-BASED
HOME CARE:**

**A Sustainable
Solution For
Europe's Elder
Care Crisis**



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A FEW WORDS ABOUT WORDS

We recognize that the preferred terminology around ageing and caregiving varies across Europe—indeed, around the world—and that there is an ongoing debate about the most accurate and respectful words to use. While we often see the terms “elderly” and “aged people” used in similar contexts, in this report we have opted to use a variety of terms interchangeably, with a primary focus on “older adults” and

“seniors”. We also recognize there is a similar debate around “carer” vs. “caregiver”. Both terms accurately define the role of a person providing care to another, and we have used both throughout the report.

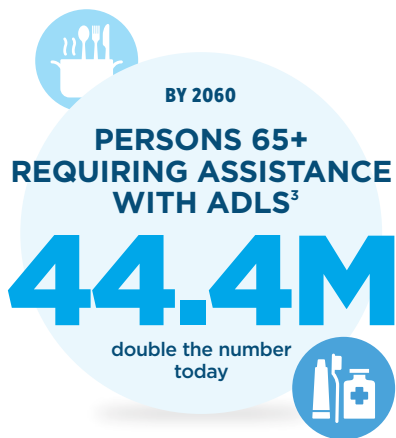
Finally, debates about grammatical style and spelling can be equally contentious. To that end, we have deferred to the **WHO Style Guide**.

Executive Summary

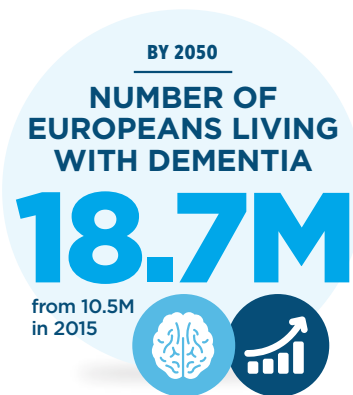


*By 2060, 155 million Europeans
–30% of the total population–
will be aged 65 or older.¹*

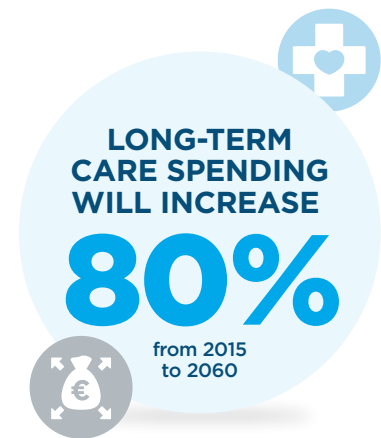
This unprecedented ageing points to a significant and growing need for care.²



The global dementia epidemic is creating a need for more complex care.⁴



Spending on long-term care is skyrocketing.⁵



Government budgets will not be able to withstand these increasing pressures on health and social care systems.

The systems in place today were created when individuals were scarcely expected to reach their 60s, let alone live well into their 70s, 80s or 90s. To meet the rapidly growing demand for elder care, many European countries are exploring ways to provide high-quality care at home. Unfortunately, however, there simply are not enough trained caregivers to match

the need, a shortfall that is expected to continue to grow. Currently, seniors and their families rely on a patchwork of options. These include government-subsidized task-based care providers, informal care from family members, friends and others, and technology interventions. While these are all important contributors to the overall care ecosystem, there is a better solution.

There is a better solution.

Relationship-based home care can help countries across Europe deliver on the promise of high-quality care for older adults.

Relationship-based home care is innovative in that it aims to keep care recipients healthy and independent, while addressing any acute needs. By putting the individual at the centre of a comprehensive care plan, relationship-based home care offers many benefits to older adults and their families, as well as to society.

Because of the highly personalized and preventative nature of relationship-based home care, every country facing an ageing population stands to benefit from emphasizing this type of care as part of its health and social care systems. But increasing the focus on relationship-based care will not be enough. Countries must also invest in building a caregiving workforce with the appropriate skills.



WHAT IS RELATIONSHIP-BASED HOME CARE?

Relationship-based home care is an innovative type of care organized around the needs of the care recipient and his or her family, rather than around the completion

of a predefined set of tasks. Relationship-based home care is often also referred to as outcomes-based home care or person-centred home care.

We urge European policy-makers and influencers to take the following actions to advance relationship-based home care:



BUILD
a body of evidence that quantifies the value of relationship-based home care, and make it a standard offering within the care ecosystem.

- » Support outcomes-based research on the merits of relationship-based home care compared to task-based home care
- » Establish person-centred, outcomes-driven standards for care
- » Integrate relationship-based home care as a central part of the care ecosystem



MAKE
a highly skilled caregiving workforce the heart of the solution.

- » Promote caregiving as a promising, fulfilling career opportunity
- » Provide professional training for carers
- » Adopt training standards that raise the bar for caregiving across the industry
- » Invest in the current and future caregiving workforce to ensure the supply of carers keeps pace with the demand



INVEST
in high-quality care as a solution for people living with Alzheimer's disease and other forms of dementia.

- » Recognize the value of Alzheimer's care in the home
- » Promote continuity of care for those living with Alzheimer's
- » Increase investments in high-quality, person-centred care for those with Alzheimer's commensurate with investments in biomedical research

Policy-makers have the opportunity and the responsibility to develop strategies to achieve these goals, tailored to their countries' specific needs and priorities.

Acknowledgements

The Global Coalition on Aging (GCOA) is pleased to share this report as a call to action to health and social care systems across Europe.

We urge policy-makers and others to anticipate the growing demand for high-quality care from Europe's rapidly ageing population and to take steps now to **(1) raise the standards for home care and (2) build a much larger pool of professional carers.**

GCOA recognizes that changes in the care ecosystem will not come about without collaboration between and among governments, the not-for-profit sector, the academic and research community and private industry. To that end, our collaboration with CARE (Caregiving

and Ageing Reimagined for Europe) was invaluable in the creation of this report.

In addition to insights from CARE and from its December 2017 publication, *Rising Need for Elder Care in Europe Necessitates New Paradigm for Elder Caregiving Training*, this report is based on an extensive review of publicly available data as well as conversations with a wide cross-section of experts on health, ageing and care in Europe. We gratefully acknowledge the following individuals for lending their time and considerable expertise to support the creation of this report:

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Executive Director, Eurocarers (Belgium)



Global Coalition on Aging

The Global Coalition on Aging aims to reshape how global leaders approach and prepare for the 21st century's profound shift in population ageing. GCOA uniquely brings together leading global corporations across industry sectors with common strategic interests in ageing populations, a comprehensive and systemic understanding of ageing, and an optimistic view of its impact. Through research, public policy analysis, advocacy and communication, GCOA shapes the dialogue and advances solutions to ensure ageing is a path to health, productivity and economic growth.



Caregiving and Ageing Reimagined for Europe (CARE)

CARE is an activity of the Campus Educational Pillar of the European Institute of Innovation and Technology on Health (EIT Health). The CARE consortium was formed in March 2015, at the initiative of Michael Hodin, CEO of the Global Coalition on Aging (GCOA), and Professor Lefkos Middleton of Imperial College London, and today includes partners from across Europe. CARE is focused on reimagining caregiving and ageing in Europe through the development of caregiving training and skills for future generations of care professionals. EIT Health partners in this project include:

Abbott Nutrition Health Institute

Aegon

City of Stockholm

E-Seniors

Global Coalition on Aging

Home Instead Senior Care

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Sorbonne University

University of Oxford

Ville de Nice

This report was supported by **Home Instead Senior Care**, the world's leading provider of home care services, operating in seven countries across Europe.



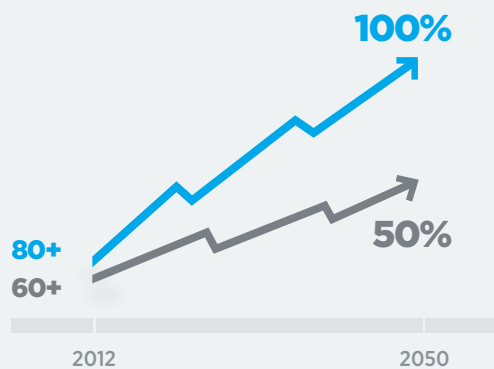
CHAPTER 1

Europeans Are Living Longer, Leading to an Increased Demand for Care

Europe is in the midst of a major demographic shift. Declining birth rates and an ageing population are fundamentally changing the makeup of European societies.

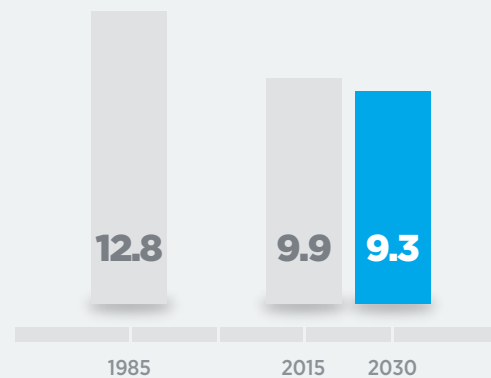
Life expectancy across Europe continues to increase.

**PROJECTED INCREASE
IN EUROPE'S SENIOR
POPULATION 2012-2050^{6,7}**



The number of younger people in Europe is steadily declining.

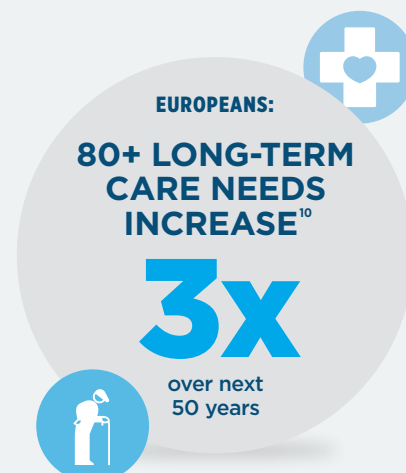
**AVERAGE BIRTH RATE
PER 1000 PERSONS PER
YEAR IN THE EU^{8,9}**



As Europe's demographics shift, care needs are increasing and becoming more complex and challenging to manage.

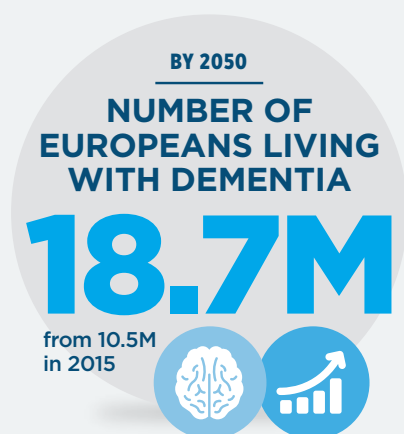
Seniors are living with disabilities and chronic conditions that affect their care needs as they age.

- Globally, more than 46% of seniors over the age of 60 have some kind of disability.¹¹
- In Europe, two thirds of people reaching retirement age will have at least two chronic conditions.¹²
- Europeans over age 65 can expect that more than half of their later years will be spent living with conditions, such as dementia or Parkinson's disease, that will affect their ability to live independently.¹³



The number of people living with dementia is on the rise.

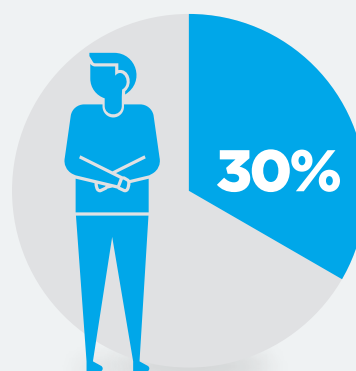
- Increased longevity is contributing to a greater number of people living with dementia. In 2015, 10.5 million Europeans were living with dementia, and by 2050, that number is projected to balloon to 18.7 million.¹⁴
- Age is the greatest risk factor for dementia. For Europeans over 65, the likelihood of developing the condition roughly doubles every five years.¹⁵



Loneliness among older adults is a growing challenge to their health and well-being.

- Almost one in three adults aged 55 and older lives alone in Europe.¹⁶
- In some European countries, such as Greece and Hungary, social isolation impacts over 40% of adults over 65.¹⁷
- The effect of loneliness on health is comparable to the impact of well-known risk factors, such as obesity, and has a similar impact as cigarette smoking.¹⁸
- Both social isolation and loneliness are risk factors for premature mortality. A US study found that greater social connection is associated with a 50% reduced risk of early death.¹⁹
- Around the globe, people aged 70 and over have the highest suicide rate of any age group.²⁰

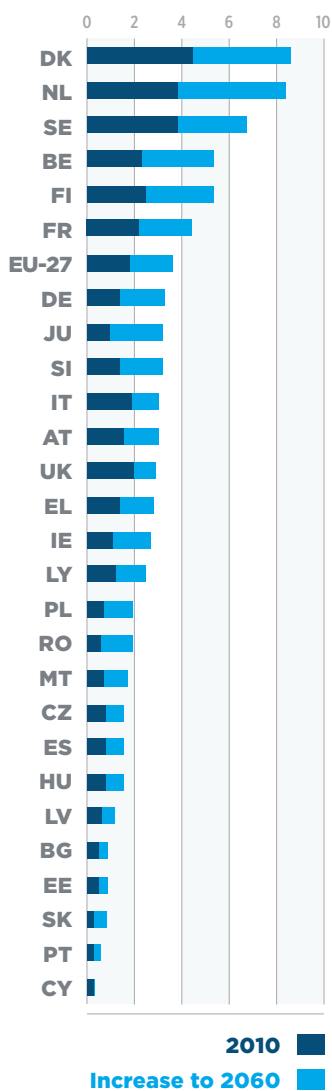
ALMOST 1 IN 3 EUROPEAN ADULTS AGED 55+ LIVES ALONE



Every country, regardless of differences in health and social care systems, must rise to a major challenge: how to ensure that older adults receive the quality care they need amid the increasing pressures on traditional care systems.

The Growing Need for Care Strains Government Resources

LONG-TERM CARE SPENDING AS A % OF GDP²³



Across European health systems, public spending on long-term care is a significant and growing proportion of countries’ health and social care budgets.

EU spending on long-term care, including home care, is projected to increase by 80% between 2015 and 2060.²¹ According to EIT Health’s CARE report, “The fiscal burden of health care is already challenging and will become unsustainable without strategic and systemic reforms. Public systems will be unable to continue taking care of elders with any degree of quality”.²²

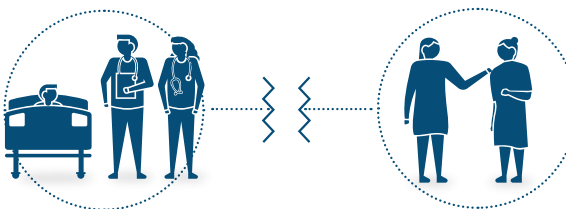
Further, the historic separation of health care and social care financing and stewardship in many European countries creates misaligned incentives across the continuum of care and a focus on discrete services rather than a holistic view of a person’s needs. For example, when hospital care and home care are managed by different governing bodies, with separate budgets, opportunities to coordinate care for better outcomes—and reduced costs—are simply not prioritized, and often missed. Experts in England report that there is now a greater expectation of partnership between health and social care systems, but budget and structural challenges remain. Overcoming the barriers to improved communication and collaboration

across these systems will help spur much-needed integration.

If countries in the EU and across Europe are to ensure dignity and quality of life for their citizens as they age, they must explore innovative ways to meet the growing need for care. In addition to closer integration of health and social care systems, strategies could include public-private partnerships, private-pay care and consumer-directed care, a flexible model that gives older adults greater control over managing their own care.

Several countries around the world have begun to experiment with different options. Germany was an early pioneer, introducing consumer-directed care in the 1990s. More recently, Australia rolled out a major elder care reform in 2017, granting seniors the freedom to choose the provider that best suits their needs and greater scope to design their own care plans. Ireland piloted a similar system in Limerick in late 2016. (For a closer look at Germany’s and Ireland’s long-term care programmes, see pages 29 and 30.)

DISCONNECT BETWEEN HOSPITAL AND HOME CARE



The Growing Need for Care Puts Pressure on Families

As birth rates decline across Europe, families are shrinking while lifespans are increasing.

By 2030, the projected birth rate in the EU will be only 9.3 per 1000, down from 12.9 per 1000 in 1985.²⁴

The total number of family carers would need to increase by 20% to 50% by 2050 in order to maintain the current ratio of family carers to elder care recipients.²⁵ Given this trend, depending on family members to provide informal care is not a sustainable solution in the face of the growing need for more (and often more intensive) care in the home.

BY 2060, THERE COULD BE AS FEW AS ONE POTENTIAL CARER FOR 51 PERSONS AGED 80 AND OLDER²¹



Moreover, family carers often need support themselves:



Studies show that carers experience more stress and depression and poorer physical health than noncarers, and those caring for individuals with dementia or Alzheimer's disease are at greatest risk.^{26,27,28}



Family carers may be forgoing educational or career opportunities due to their caregiving responsibilities, and businesses are likely losing productivity. Comprehensive data are not available for Europe, but two studies from the US suggest a significant impact: a 2015 study estimates lost income due to informal caregiving at \$522 billion per year, while a 2010 study estimates that employee caregiving costs businesses as much as \$34 billion per year in lost productivity.^{29,30}

Growing Demand for Home Care Exceeds the Supply of Qualified Carers

Given ageing and health trends, Europe faces a potentially significant shortfall of qualified carers.

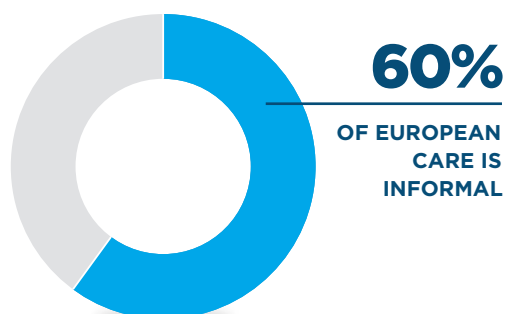
The vast majority of older Europeans—like their peers around the world—would prefer to continue living in their own homes as they age.^{32,33} And policy-makers across Europe are increasingly encouraging care in the home as an economical alternative to institutional care.^{34,35}

Unfortunately, there simply are not enough carers to meet the growing demand for quality home care. Those who provide care in the home may be roughly divided into three types:

- 1. Professional (or paid) care workers,** who are usually trained and employed by government agencies or by licensed social services agencies, charities, or private-sector care companies;
- 2. Informal carers,** including family caregivers, friends and neighbours; and
- 3. “Grey-market” carers,** who are not affiliated with agencies or government programmes, and are typically unregulated and untrained.

Today, about 60% of care in the EU is provided by informal carers.³⁶ Informal carers are defined as providing “help to someone with a chronic illness, disability or other long-term health or support need, outside a professional institution or formal framework”.³⁷

When carers are paid directly by care recipients or families outside of government regulation or agency oversight, there is no way to ensure high-quality, person-centred care. While grey-market carers can provide respite for families, they may not have relevant training or language skills, potentially contributing to poorer outcomes. Older adults and their families are increasingly resorting to grey-market care when they cannot support the full caregiving burden themselves and when professional carers are either unavailable or too expensive. The care workforce in some countries is heavily dominated by unregulated and untrained carers.³⁸ For example, of the more than 2 million care workers in Italy, only about 700 000 are formally employed.³⁹



CHAPTER 2

Relationship-Based Home Care: Delivering on Europe's Promise of High-Quality Care



Home care from trained professionals offers a sustainable option for providing the high quality of care European seniors need, want and deserve.

While public expectations around care responsibilities vary across European countries, the experts consulted for this report agreed on several key characteristics that define high-quality care:

- Is person-centred, focusing on the physical and emotional needs of the senior;
- Supports families and family carers in their relationship to the person receiving care;
- Enables coordination across the entire care team, which encompasses all of those engaged in a person's care, including family carers and health care providers;
- Recognizes that the needs of care recipients continuously evolve; and
- Is outcomes-based, taking a preventative approach to allow for the highest quality of life and independence for as long as possible.

Integrating relationship-based home care as a preferred option among the available care offerings will empower countries to deliver on the promise of high-quality care for their seniors.

“ *Continuity of care is a major challenge for older adults and their families. It is emotionally draining and disorienting to constantly have a new person in your home who doesn't know you and doesn't know your needs, your likes and dislikes, or your daily routine”.*

Rick Greene
Executive Director, International Alliance
of Carer Organizations



Relationship-Based Home Care: Delivering Impact vs. Inputs

Home care aims to help people maintain healthy and active lifestyles in the comfort of their own homes. In many government-funded care systems, home care is organized around a specific set of tasks, such as assisting with bathing, helping a person dress or cooking a meal. Each task has a specific time expectation, and an older person may receive as many as four or five visits from as many different carers in a given day.

Relationship-based home care, on the other hand, is highly personalized, organized around the needs of the care recipient and the care recipient's family. Often referred to as outcomes-based or person-centred care, this type of care focuses on broader benefits, such as promoting independence, ensuring physical and emotional well-being and supporting the continuous monitoring and evaluation of care needs over time.

Relationship-based home care is most often provided by a professional agency that assigns a dedicated care team to coordinate the delivery of high-quality care. Professional carers receive training on how to assist with activities of daily living (ADLs) and how to care for chronic conditions, such as diabetes; they may also be trained to understand and respond appropriately to changes in mood brought on by dementia. Instead of focusing only on acute needs, relationship-based home care takes a holistic approach. While typically more resource intensive than task-based care, investment in this type of care brings value to older adults, their families, the healthcare system and society.

“ When evaluating quality care, we have created a clear structure that moves beyond a ‘compliance’ or ‘tick-box’ approach to a more holistic, person-centred assessment. Care should focus on the impact rather than on the inputs because people want a life, not a service”.

Andrea Sutcliffe CBE
Chief Inspector, Adult Social Care,
Care Quality Commission, England

Relationship-Based Home Care Benefits the Care Ecosystem, Individuals and Society

BENEFITS TO THE CARE ECOSYSTEM



Reduced Health and Social Care Costs

By facilitating early intervention and ongoing assessment of care needs, relationship-based home care reduces costs by decreasing hospital admissions, re-admissions and doctor visits.^{40,41} It can also reduce the length of hospital stays and ensure that people have access to the support they need once they are discharged.^{42,43} Ensuring a safe environment for ageing is a critical risk reduction factor. One in three people over the age of 65 and one in two over the age of 85 fall every year, often with serious health consequences.⁴⁴ Providers of relationship-based home care help to ensure that spaces are safe and provide support through daily tasks that may otherwise result in a fall.



Better Coordination Across the Care Team

With relationship-based home care, the professional care provider often becomes familiar with the care recipient's entire care team—including his or her family members, physicians, nurses, pharmacists and others. This familiarity can be particularly beneficial in settings where privacy regulations make it difficult to share health information. According to the experts consulted for this report, a care relationship that puts the individual—rather than a checklist—at the centre of the care plan supports better coordination of care and navigation of the health system. Coordinated care contributes to more consistent adherence to medication regimens, among many other benefits.⁴⁵

“ The care needs of seniors can change every day. Integrating care and care management through a dedicated care team helps ensure that an individual's needs continue to be met, even as they evolve.”

Dr François Höpflinger, PhD
Professor of Sociology, Steering Group Member,
Center for Gerontology,
University of Zürich

WHY DOES MEDICATION ADHERENCE MATTER?

“ Increasing the effectiveness of adherence interventions may have a far greater impact on population health than any improvement in specific medical treatments.”

World Health Organization⁴⁶

Older adults, particularly those with multiple chronic conditions, can have complex medication regimens that may be difficult to follow. Failure to do so can risk a negative impact on health and create avoidable discomfort. Faithful adherence to a prescribed regimen is vital to maintaining health, managing chronic conditions and supporting activities of daily living.

- Nearly 200 000 people across the EU die each year because of medication nonadherence.⁴⁷
- Medication nonadherence costs the United Kingdom's National Health Service an estimated £500 million (€567 million) per year.⁴⁸

Carers trained to focus on safety and positive outcomes have a critical role to play in preventing adverse effects that may be associated with medication mismanagement.

BENEFITS TO OLDER ADULTS AND THEIR FAMILIES



Enhanced Emotional Well-Being

Home care that puts the older person at the centre of care facilitates the development of strong and trusting relationships between carer and care recipient. The care experts who contributed to this report affirmed the powerful impact of this bond, which can decrease feelings of loneliness and depression, two growing dangers among older adults and carers.



Better Care for People Living With Dementia

Alleviating feelings of loneliness can significantly decrease the risk of the onset of dementia.⁴⁹ Further, the ability to remain in a familiar environment can reduce anxiety in people with Alzheimer's disease, who may find the adjustment to a new setting traumatic. Data from the US show that relationship-based care in the home leads to fewer doctor visits and fewer hospital admissions for people with dementia, compared with those without home care.⁵⁰ The result: lower costs and higher quality of life.



Greater Trust and Comfort in Caregiving

Continuity of care is a critical component of high-quality care, particularly for those living with dementia.^{51,52} With relationship-based home care, the carer knows the care recipient, her needs and preferences, and often her family. The presence of familiar carers means there is no need for older adults and their families to continuously reorient to new carers, which is often the case when carers are assigned to tasks and not individuals.



Greater Flexibility and Peace of Mind for Families

Caring for a loved one can place an enormous amount of stress on the family carer, leading to social isolation and compromised health. A US study shows that up to 70% of family carers have clinically significant symptoms of depression.⁵³ By involving the needs of the entire family, relationship-based home care eases the burden on family carers. Further, the knowledge that their family member is well-cared for by a trusted professional carer brings peace of mind.

“ My parents have been married for 57 years and could not imagine growing old in a nursing home. I live in London and visit my parents in Switzerland often, but I cannot care for them full-time. I am so grateful for their attentive caregiver; she's practically a member of the family!”

Family caregiver from England

“ Every day, my caregiver and I discuss what we are going to make for lunch. She knows that I like to help in the kitchen, so she brings everything to the table so that I can help prepare. Although she could easily make everything on her own much quicker, this simple act helps improve my self-confidence”.

Care recipient from Switzerland

BENEFITS TO SOCIETY



Increased Employment Opportunities

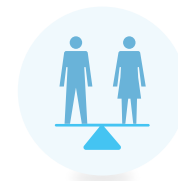
European demand for professional carers is expected to double by 2050.⁵⁴ Growing the home care workforce can be an important economic driver and job creator for European countries. In Ireland alone, it is estimated that the demand for carers will grow 28% from 2006 to 2021.⁵⁵ By growing the pool of professional carers, European countries can create valuable job opportunities for underemployed populations, including older adults wanting to stay active and extend their careers, refugees and youth.

As the professional care field creates workforce opportunities, it also provides income stability and a rewarding career pathway for purpose-driven individuals. For individuals just beginning their careers, a job in relationship-based home care provides ongoing training and development opportunities and can provide a path for advancement in the ever-growing fields of healthcare, geriatrics, gerontology and nursing, as examples.



Greater Job Satisfaction and Retention of Professional Carers

According to the European care experts interviewed for this report, person-centred care is more rewarding for carers than giving them a checklist of tasks to complete. Research from the US suggests that carers who are able to bond with the seniors whom they care for report high levels of personal satisfaction and well-being.⁵⁶



Increased Gender Equity

Around the world, caregiving responsibilities within families disproportionately fall on female family members. Europe is no exception; in Spain, for instance, 84% of family carers are women.^{57,58} Family caregiving obligations force many women to leave full-time jobs or cut back on their work hours. By reducing the care burden on wives, daughters and sisters, relationship-based home care can contribute to gender equity in the workplace and across society, and support economic growth.

“ Working-age carers are at a higher risk of poverty. For this group, caregiving is associated with a higher probability of experiencing poverty across all countries, except in southern Europe. Women carers appear to be especially vulnerable to poverty risks”.

OECD⁵⁹



Michael Stommel

SWITZERLAND

I've always enjoyed working with and being surrounded by people. My first experience as a caregiver was looking after my mother, who suffered from dementia, and my father, who needed a wheelchair to move around. I enjoyed spending time with my parents and working to make their lives as comfortable and enjoyable as possible. So, becoming a full-time caregiver was a natural transition—although the work is quite different from my earlier careers as a dispatch manager and a correctional officer.

To me, caregiving is so much more than a job, giving me the opportunity to develop connections and build trust with my clients. It's important to me that I contribute to the quality of life of my clients, and I aim to bring joy to every interaction. For example, once I helped a client overcome her fear of the stair lift by suggesting that we sing a popular folk song, and now she proudly sings that tune every time she operates the lift.

I like to get to know my clients, learn about their interests and help them to enjoy the present and connect to their past. Creating memorable experiences—like helping a client pick hard-to-reach blackberries in her backyard—can really make a difference in people's lives.

In addition to coordinating excursions and meetings with friends, I document these occasions to share with my clients' families so they can reminisce together. Through caregiving, I help to bring families closer together and alleviate the burden of caring for a family member. And it's so gratifying to be welcomed and appreciated for this work.

“To me, caregiving is so much more than a job, giving me the opportunity to develop connections and build trust with my clients”.

A young woman in a white lab coat is smiling and holding the hand of an elderly woman. The elderly woman is looking up at the young woman with a smile. The background is a blurred indoor setting, possibly a home care environment. The entire image has a blue tint.

CHAPTER 3

Expanding Europe's Capacity to Care: Overcoming Barriers to Integrating Relationship-Based Home Care in the Care Ecosystem

The demand for relationship-based home care is growing.⁶⁰ According to the experts who contributed to this report, older adults and their families are increasingly choosing to pay for such care even when it is not funded by public health or social care systems.

Several European countries are exploring an expanded role for relationship-based home care to better meet the needs of their ageing populations. Both consumers and governments are starting to recognize that relationship-based home care represents a way to spend *smarter* on elder care, rather than simply spending *more*.

To capitalize on the benefits outlined in this report, policy-makers and leaders of health and social care systems across Europe must tackle the barriers to making relationship-based home care a valued component of the care ecosystem. On the following pages, we highlight each of these barriers and what must be done to overcome them.

“ Care at home is the basis of a good life in old age. It must become a central part of countries’ policies. While most of the systems work today, many are too fragmented and unprepared to meet future needs. Policy-makers need to strategize today for how they will continue to ensure care for their citizens over the long term. Here in the UK, there’s a movement to bring the different health and social care systems together. It’s absolutely vital that we do”.

Baroness Sally Greengross OBE
President and Chief Executive,
International Longevity Centre-UK,
and Member, House of Lords





BARRIER 1:

Government-funded programmes primarily fund task-based home care.

Public spending on relationship-based home care, which is typically more resource-intensive than task-based care, represents a relatively small percentage of overall care spending. Yet, by improving health outcomes for seniors,

investments in relationship-based home care would yield savings elsewhere in the care ecosystem—savings that could be reinvested in providing more and better care.



CALL TO ACTION:

Build a body of evidence that quantifies the value of relationship-based home care, and make it a standard offering within the care ecosystem.



Support outcomes-based research on the merits of relationship-based home care compared to task-based home care:

Governments and care providers must work together to evaluate the successes and shortcomings of today's care system and better understand the role of relationship-based home care. More specifically, investments in robust research that directly compares the short- and long-term impacts of task- vs. relationship-based care on older adults, their families and national health systems are desperately needed.



Establish person-centred, outcomes-driven standards for care:

Care standards should move away from focusing solely on compliance (i.e., a checklist and timed approach) to a more holistic approach to care (i.e., person-centred and outcomes-based).

“The growing use of remote monitoring and other new technologies in home care is a wonderful development. With technology managing some of the basic care tasks, carers are able to devote more time and attention to the person they're caring for.”

Sharon Allen OBE
CEO, Skills for Care



Integrate relationship-based care as a central part of the care ecosystem:

New funding, incentive and stewardship models that expand opportunities for relationship-based care—such as integrated health and social care systems, private-pay care and consumer-directed care—would place older adults and their families at the centre of care services, supporting more effective care as well as improved continuity of care. Further, enabling a wider range of qualified providers, including the business sector, would encourage growth of relationship-based home care as a valuable source of employment and skill development.

BARRIER 2:

Caregiving is not valued as a career of choice.

For too long, caregiving has been viewed as an unskilled, low-paying job.⁶¹ Often professional carers are not respected for the physically and emotionally taxing work they do. Caregiving is a challenging profession, requiring intensive training. More importantly, it demands workers who have a desire to help others and serve the elderly. While technology can replace some of the tasks associated with caregiving,

these are jobs that will always require the personal interaction and caring touch that only a human being can provide.

Europe needs to attract more carers to the field and ensure that they are trained to meet high professional standards. Further, efforts are needed to dispel the misconception that caregiving is a field with no career progression. In fact, it can be a fulfilling career for purpose-driven individuals and can be the first step toward careers in nursing, geriatrics, other medical fields, social services and business—for all ages.

CALL TO ACTION:

Make a highly skilled caregiving workforce the heart of the solution.



Promote caregiving as a promising, fulfilling career opportunity:

The simple fact is that there are not enough trained carers to provide the care that Europe needs now—let alone in the coming decades. Public awareness efforts to highlight opportunities in the caregiving field can change perceptions, positioning professional caregiving as a personally and financially rewarding career and shining a light on the growing demand for people in these roles. Faced with a shortage of carers, the UK is considering launching a campaign to promote caregiving as a profession, underscore its value and attract more people to the field.



Provide professional training for carers:

Expanding Europe's capacity to care demands top-notch training for carers. This training not only must address the practical aspects of assisting older adults with chronic conditions and activities of daily living, but it also must teach core communication, language and interpersonal skills to ensure that care is delivered with dignity, respect and empathy.

Such training could be delivered through workforce development programmes for underemployed groups, following appropriate screening to identify candidates with service values. Online modules, such as those developed by EU CARE, provide easy, cost-effective access to high-quality carer training (see page 26).



Adopt training standards that raise the bar for caregiving across the industry:

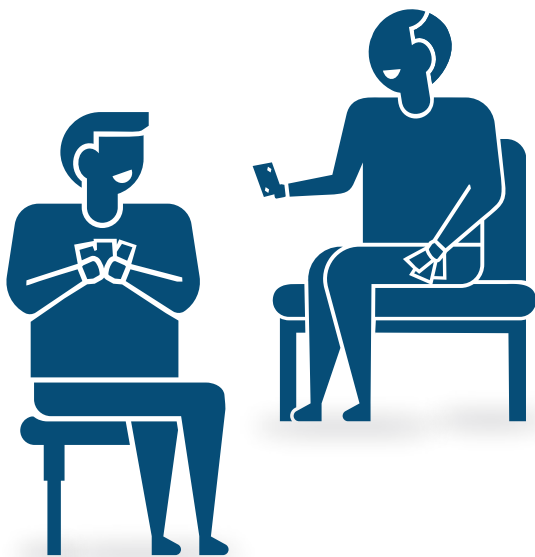
While care providers such as Home Instead Senior Care set the highest standards for training and skill development, most carers remain focused on executing tasks. Government and care providers must work together to define best practices, ensure consistent and transparent standards for all carer training and build public trust in the home care industry. Partnerships between the public and private sectors could help pilot and bring successful models to scale. Standards also support learning opportunities that allow carers to earn distinctive credentials—such as special skills in caring for people with dementia—and improve their value in the marketplace.



EU CARE PROVIDES HIGH-QUALITY, AFFORDABLE TRAINING

The Caregiving and Ageing Reimagined for Europe (CARE) CAMPUS initiative, part of the European Institute of Innovation and Technology on Health (EIT Health), is a novel approach to elder care training. CARE CAMPUS builds carer skills through a widely accessible e-based learning curriculum. By moving from the classroom to the cloud, CARE CAMPUS offers carer training to anyone, anywhere,

at relatively low cost. The CARE CAMPUS curriculum includes critical health areas for older people, such as cognitive decline, skin, oral and nutritional needs and palliative care. This training is intended to support ageing in place through improved care quality while also increasing employment in the growing care field.



Invest in the current and future caregiving workforce to ensure the supply of carers keeps pace with the demand:

In order to attract high-quality talent to home care, providers and consumers must be willing to pay wages for carers that reflect the skills and responsibilities of the profession. Caregiving is not a job that can ever be replaced by gadgets or robots. It demands a high degree of personal commitment and a passion for serving others. Recruiting and investing in this workforce must be a priority for governments and private care providers across Europe.

“ Ensuring that Europe’s carers are trained not just in care activities but also in language and communication skills is critical to our ability to provide high-quality care for the elderly. The need for language training for carers is growing in importance as more immigrants recognize caregiving as a promising career opportunity.”

Professor Lefkos Middleton MD, FRCP
Chair of Neuroepidemiology and Ageing Research,
School of Public Health, Imperial College London,
and Chair, EIT Health CARE CAMPUS Consortium

BARRIER 3:

The focus on curing Alzheimer's overshadows the powerful role of caring for those with the disease.

Based on the current pipeline of drugs in development, effective treatments for Alzheimer's disease are years, if not a decade or more, away. While investments must be made in finding ways

to prevent Alzheimer's and treatments that will allow people to live their fullest lives, for those afflicted with the disease now, care can make an enormous difference in their quality of life.

CALL TO ACTION:

Invest in high-quality care as a solution for people living with Alzheimer's disease and other forms of dementia.



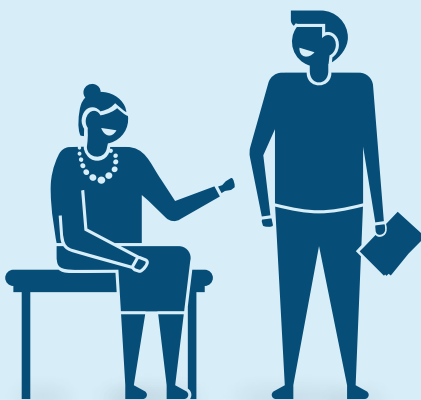
Recognize the value of Alzheimer's care in the home: Familiar surroundings and a stable routine are key to one's ability to live as independently as possible with Alzheimer's disease.⁶² A carer in the home focused on maintaining a routine and monitoring for changes in behaviours not only extends quality of life for the individual with Alzheimer's, but also brings peace of mind and health benefits to family carers who struggle (physically, mentally and emotionally) with their caregiving responsibilities.



Promote continuity of care for those living with Alzheimer's: Care for those with Alzheimer's disease can be greatly enhanced by having a consistent care team, including carers and managers who develop rapport over time with the individuals receiving care and their families. The lack of coordination associated with poor continuity of care can lead to high healthcare spending and adverse outcomes for people with dementia.⁶³ Further, data has shown that relationship-based care for those with Alzheimer's results in fewer doctor visits and fewer hospital admissions, leading to overall better quality of care and lower costs to the health system.⁶⁴



Increase investments in high-quality, person-centred care for those with Alzheimer's commensurate with investments in biomedical research: While public and private investment in finding effective treatments for Alzheimer's and other dementias is on the rise, this provides no relief for individuals and families already struggling with dementia. For those living with the disease today, investments in relationship-based care are imperative for maintaining quality of life and managing overall healthcare costs. At the same time, we must ensure that funding for both cure and care increase commensurate with the impact of the disease.





Sally Bradford

ENGLAND

After spending two years at home supporting my teenagers through secondary school and A-Levels, I decided it was time to get back into work.

My friend Jan really loved her work caring for older people, but I'd heard some negative stories about working in care. When Jan told me that she sees her clients for at least an hour and is matched with them based on shared hobbies and interests, it sounded like the perfect career path after spending nine years as a special needs teaching assistant in a primary school. Now I work anywhere between 10 and 38 hours each week and enjoy having the flexibility to organize my schedule around family life.

My training has completely changed my outlook on older people, as has my experience since my dad's diagnosis of Parkinson's disease about a year ago. Not only does Dad need lots of help and support from Mum to continue living a happy and healthy life, but the days can be physically, mentally and emotionally challenging for Mum too. It really comes down to having a good support system.

I know that my weekly visits with my client Wendy, who lives with dementia, and her husband David,

are a lifeline. Being a full-time carer for your spouse means 24 hours a day, seven days a week. Each Monday, I take Wendy to all sorts of lovely places—National Trust properties, garden centres, antique shops—and it's a privilege to spend time with her. The hardest part is that no matter how much we enjoy ourselves, she can never go back and tell David what she's done

“When Jan told me that she sees her clients for at least an hour and is matched with them based on shared hobbies and interests, it sounded like the perfect career path”.

and where she's been, as her memory is just no longer there. That's tough, but the reward is knowing that Wendy has had a ball whilst giving David a few hours of respite.

This is the first role I've had where I look forward to coming back to work after a holiday because I can't wait to find out what my clients have been up to!

Here are two examples of countries that have structured their care systems to allow consumers greater control over determining who provides their care, how much care and how that care is paid for.

GERMANY: A FLEXIBLE MODEL FOR CARE

“We need to change what we’re doing and attract more carers to the profession. Carers work with too many individuals to develop the sort of relationships that seniors value, and then being overworked stresses the carer. It’s a vicious cycle. When people see stressed carers, they don’t want to enter the field, but that means more carers will be overworked”.

Sabine Jansen
Executive Director, German
Alzheimer’s Association

Germans participate in the national long-term care system well before they need it: starting with their first job. Care in Germany is funded through long-term care insurance, with an individual and his or her employer contributing a combined 2.55% of wages on an annual basis.⁶⁷ Once a senior needs care, he or she applies to the Social Health Insurance Medical Review Board. Following the application, a nurse visits the home and conducts a needs assessment, which determines the individual’s care budget.

Under Germany’s consumer-directed care system, individuals are free to choose how to spend their care budgets. Since Germany first introduced consumer-directed care in the early 1990s, several other countries, including South Korea and Austria, have designed long-term care systems based on the German model.



TOTAL
POPULATION:⁶⁵

80.6M

NUMBER OF
PEOPLE AGE 65+:⁶⁶

17.8M

Nearly three quarters of Germans needing care remain at home, and there is a wide range of approved providers available, with 13 000 agencies throughout the country and upwards of 100 agencies in each of the larger cities.⁶⁸ German Care Insurance (GCI) payments can cover specific tasks or an amount of time (about 10 hours per week) that a carer may spend with a care recipient. If an individual wants to receive more care, he or she can pay out-of-pocket—and more than one third choose to do so. While most agencies provide task-oriented services, an increasing number of care providers are recognizing the value of providing a relationship-based model to German seniors.

Looking forward, Germany’s programme faces at least two significant challenges. First, as the population ages, there will be fewer people paying into the long-term care insurance system, raising questions about the sustainability of the system and affordability of the care provided. Second, the demographic shift means that demand for high-quality carers may soon outstrip the supply.

GERMANY’S LONG-TERM CARE PROGRAMME AT A GLANCE

STRENGTHS

- » Universal coverage, by way of mandatory long-term care insurance system.
- » Choice of carer: wide variety of provider options allows Germans to pick the best fit for them.
- » Flexibility: seniors and their families may decide the timing of care visits.

CHALLENGES

- » Individual care budgets are not high enough to provide as much care as people may want.
- » Rural residents may have less access to care than urban residents.
- » Most agencies provide task-oriented services, with each visit lasting between 5 and 30 minutes.

IRELAND: AN EVOLVING CARE LANDSCAPE



TOTAL
POPULATION:⁶⁹

5M

NUMBER OF
PEOPLE AGE 65+:⁷⁰

655 000

Home care in Ireland is managed by the Health Service Executive (HSE), a government body responsible for healthcare and social services. Home care is funded by the government through a variety of models, including, but not limited to:

- Tax relief for home care services purchased on the private market;
- A carer's allowance for family members providing 4+ hours of care per day;
- Home Help: free, domestic and personal care support;⁷¹ and
- The Home Care Package system, Ireland's primary method of home care provision for medium-to-high support needs.⁷²

It is estimated that more than 14 000 care recipients over age 65 received a formal home care package (HCP) through HSE in

2016.⁷³ These packages are primarily task-oriented, with an average of one to three 1-hour visits per day.

Older adults in need of care submit an application. A public health nurse conducts an assessment and estimates the number of care hours needed per week. The care recipient then selects a provider from a pre-approved list that includes charities, private companies and HSE itself, and HSE coordinates care directly with the provider.

Like Germany, Ireland faces several critical challenges, including how to maintain the sustainability and affordability of its system as the population ages and care needs increase.

From September 2016 to November 2017, an experimental programme in Limerick piloted a consumer choice model offering seniors a wider variety of care options. In lieu of a predefined care package, the pilot granted seniors a specific Euro allotment based on the number of care hours needed multiplied by the average hourly care rate across all participating providers. Seniors and their families were free to decide exactly where, when and how to spend their allotment. The goal of the programme was to experiment with shifting the government from being the care provider to being the care payer and overseer.

IRELAND'S LONG-TERM CARE PROGRAMME AT A GLANCE

STRENGTHS

- » Choice of care provider: Seniors can choose from a list of public, non-profit and private providers.
- » Choice of funding mechanism: Ireland's system offers different funding options, such as tax relief, a carer's allowance or a home care package.
- » Governmental recognition of preference to age in place and cost-effectiveness of home care.

CHALLENGES

- » Despite choice, some provider types are not available in certain locales, especially in rural areas, largely due to lack of payment for carer travel costs.
- » Home care packages are primarily short shifts and task-based care, contributing to the undesirability of home care as a career.
- » Growth in care needs over time puts strain on government budgets.

Conclusion

At a time when Europe's population is ageing at unprecedented rates, relationship-based home care provides a solution that improves outcomes for older adults, reduces burdens on families, creates fulfilling jobs and eases the pressure on overburdened care systems.

Addressing the barriers identified in this report will lead Europe towards a more sustainable, respectful approach to caring for older adults, today and in the future. Relationship-based home care provides a bridge between health and social care, institutional care and other support services. It helps older people to successfully navigate the health system and remain independent with a high quality of life. Ultimately, the best strategy to achieve these goals, and fund them, will vary based on each country's needs and priorities. **But the time to act is now.**

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