



LIVING WELL WITH DEMENTIA

# 2030 – A VISION FOR A DEMENTIA-FRIENDLY SOCIETY



[bupa.com/dementia](https://bupa.com/dementia)



**With ageing populations and the number of people living with dementia set to rise everywhere, especially in low and middle income countries<sup>1</sup>, dementia is a truly global challenge. 2015 marks a critical stage in the journey towards a future where people understand dementia – currently affecting 44 million people worldwide – including how they can reduce their risk, and helping those living with dementia to live well.**

**Looking ahead to 2030, the number of people with dementia is estimated to increase to 76 million<sup>1</sup>.**



Fortunately, the journey has already begun, but there is a lot more work to do. Faced with the social and economic challenge of ageing populations, and the fact that more people will stay longer in work and alongside duties of care, we have a global need for a dementia-friendly society.

Aspiring to a vision for a society which puts people first and dementia second, culturally and within communities, living spaces, workplaces, and care environments, reveals that there are fundamental changes which must be achieved now.

The future is closer than we think – and what we do today will impact the future course of dementia. Indeed, many of these changes in terms of how we recognise, prevent, diagnose and support people living with dementia need to have been completed ‘yesterday’. Whilst it is certain that evolving technology will start to play a bigger role, the hardest changes to achieve will be behavioural and attitudinal – and there is much to be done.





Global health and care companies such as Bupa and organisations such as Alzheimer's Disease International (ADI) and The NCD Alliance (Non-Communicable Diseases Alliance), are also setting important goals towards achieving a society where people understand dementia as a non-communicable disease in the way they do cancer, diabetes and heart disease, and the common risk factors. By calling on health ministers and policymakers to enable people with dementia to live well today in addition to reducing the risk of dementia in the future, this is a vision that can be achieved. Looking ahead to 2030, ADI and Bupa's joint Dementia Charter<sup>ii</sup> can become a reality, outlining the rights of people living with dementia, wherever they are in the world.

Marc Wortmann, Executive Director, Alzheimer's Disease International, explains:

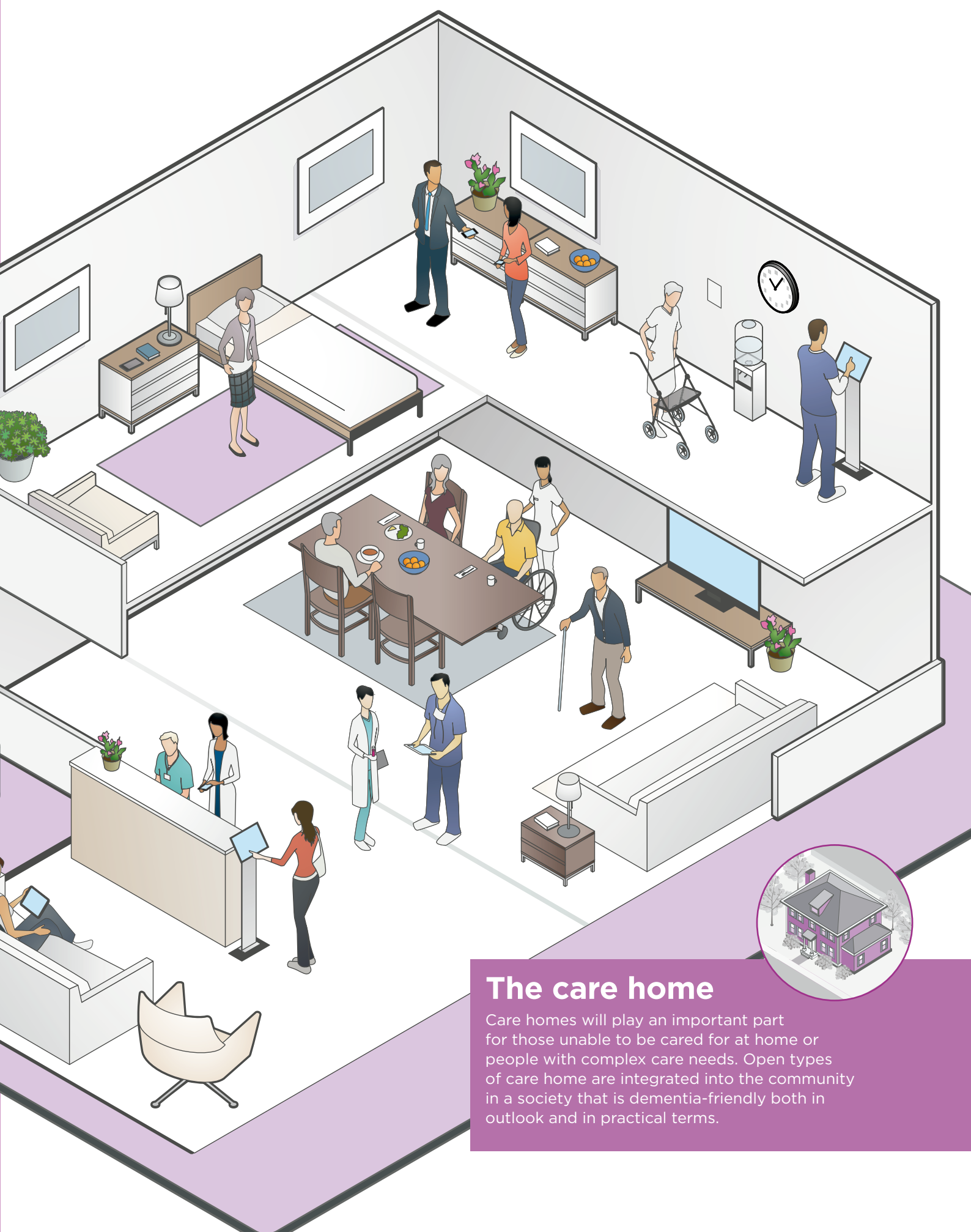
**“Alzheimer's disease and other forms of dementia must become a national and international public health priority today, so countries have adequate care and support systems in place to look after people living with the condition in the future.”**

Marc Wortmann

So what is dementia and why is it such an issue now? More fundamentally, why has the world been so slow to embrace challenges of the mind, when popular medicine caters so comparatively well for diseases which affect individual or groups of organs? If you have a cancer diagnosis for example, you can expect to be seen by a specialist and your treatment prioritised within a very short timeframe. Why isn't the same true of dementia?

Dementia is a broad term which describes a set of symptoms that develop as a result of damage to the brain. It is progressive and irreversible. Symptoms may include memory loss, difficulty communicating and changes in mood. In the later stages, people with dementia become unable to carry out everyday activities and will need increasing amounts of support. There is no cure for the condition. Alzheimer's is the most common form of dementia and accounts for 50%-70% of cases<sup>iii</sup>. Vascular dementia is the second most common type<sup>iv</sup>.





## The care home

Care homes will play an important part for those unable to be cared for at home or people with complex care needs. Open types of care home are integrated into the community in a society that is dementia-friendly both in outlook and in practical terms.

# Dementia: it's everyone's business

**Professor Graham Stokes, Global Director of Dementia Care at Bupa, an author, clinician and an internationally recognised authority on dementia care practice and policy, clarifies the current situation:**

**“As we address dementia today and also in the future, we need to put the person they are at the centre of their care – treat people living with dementia as unique individuals, understanding who they are, their life story, and the reality in which they are living.”**

Professor Graham Stokes

“People are living longer and countries have to cope with rapidly ageing populations. At the moment, only around half of people living with dementia in high-income countries actually get a diagnosis. In developing countries, it's only around 10%. While these numbers should improve slightly in the next few decades, the reality is that countries with emerging economies will have huge numbers of people living with dementia, of which the vast majority will remain undiagnosed. This puts an enormous strain on families and communities, as they won't have access to the support they need.”

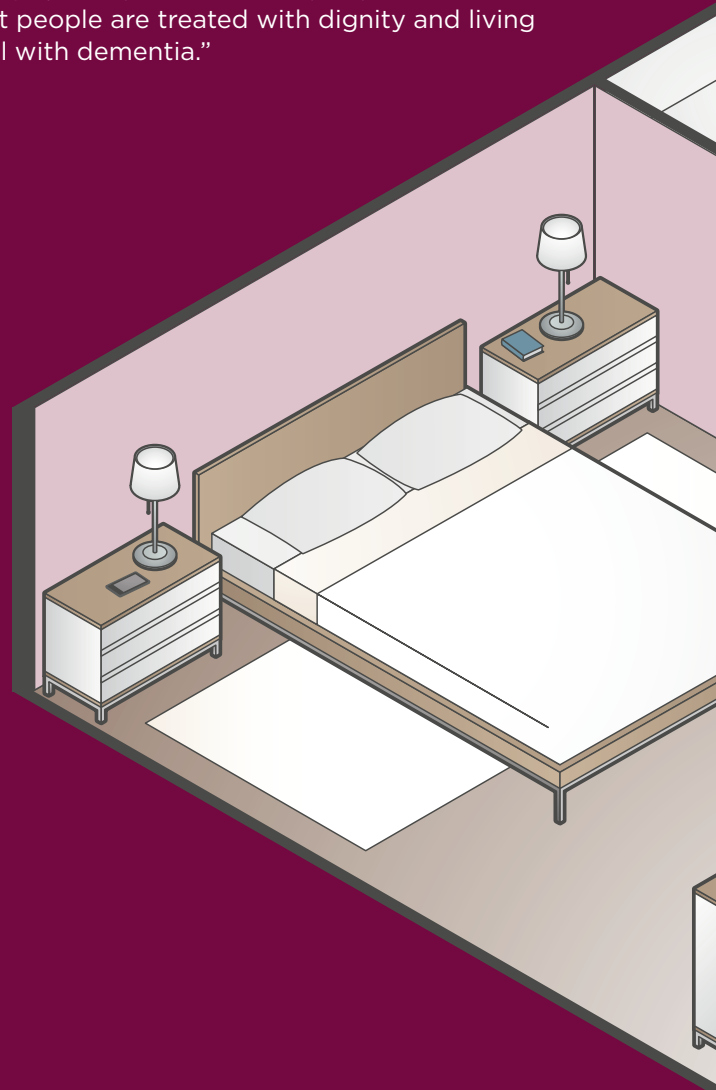
Dr. Fiona Adshead, Chief Wellbeing and Public Health Officer at Bupa, adds:

“Whilst many developed countries spend a huge amount on the end-care of dementia, we have not yet adopted the cultural change that is needed to help people with dementia not only live, but *live well*. This is what is urgently needed if we are to achieve a vision for 2030 where we see beyond the diagnosis and think of a person with dementia as a valued and participating member of society.”

One of the biggest issues is making dementia relevant and addressing public misconception, fear and apathy. In doing this, the dementia challenge must be seen as relevant to everyone, whether schoolteacher, employer, carer, managing physician or nurse.

Dr. José Francisco Tomás, Chief Medical Director, Bupa Spain and Latin America Domestic, adds:

“In 2030, I'd love to see a different approach to how we care with people living with dementia. We need a multidisciplinary approach, just as with cancer, medical and care professionals including neuropsychologists, neurologists, expert carers and physiologists all working together to ensure that people are treated with dignity and living well with dementia.”



For Margaret Ryan, Head of Dementia Services, Bupa Australia, the next 15 years need to focus on overcoming the stigma attached to dementia and creating better health and care pathways:

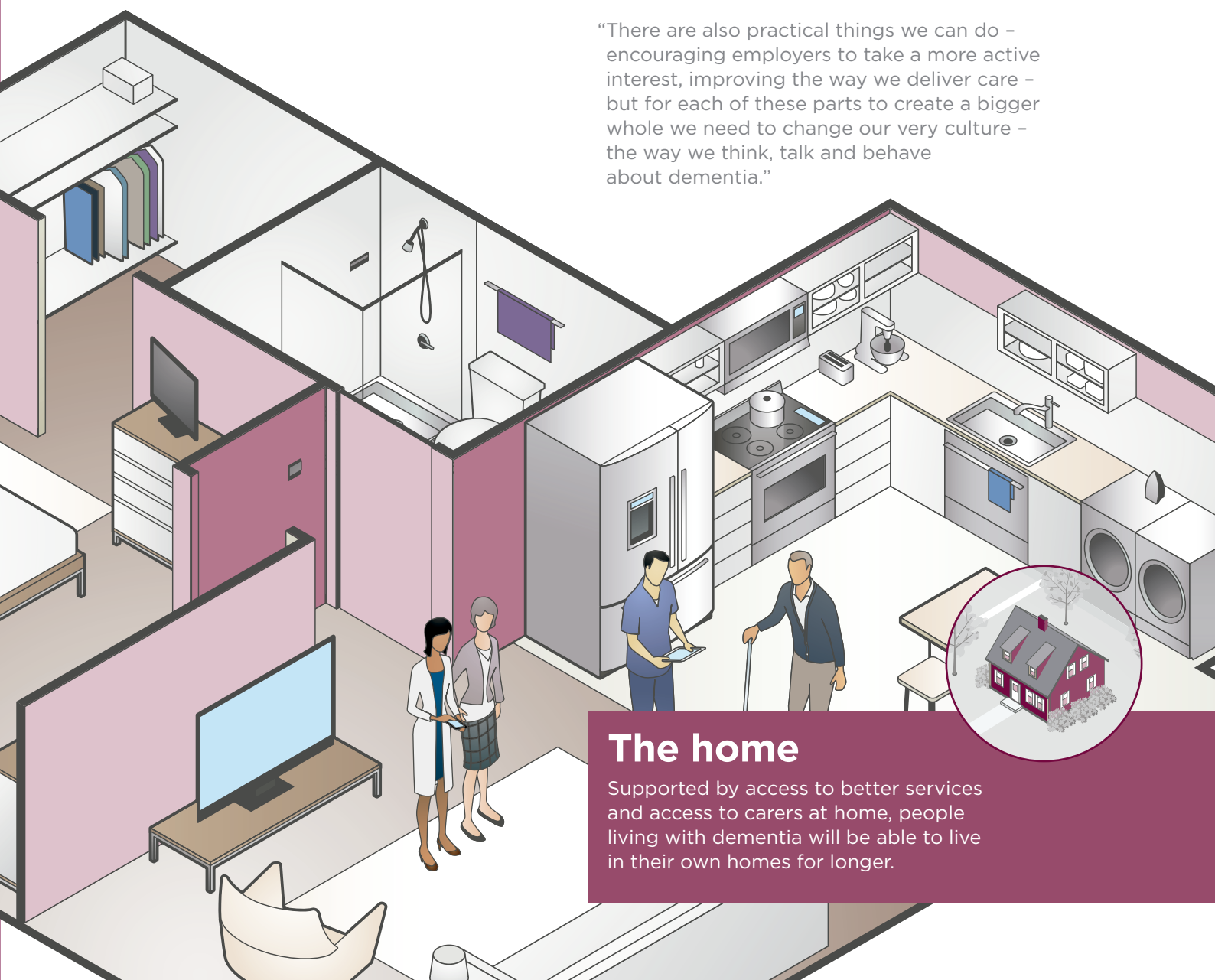
**“Smashing stigma and creating better care go hand in hand.”**

Margaret Ryan

“It means you change the conversation to focus on encouraging early diagnosis, promoting living well with dementia, and keeping the mind and body active.”

“New Zealand is a good example of a government leading a unified approach to help individuals and families that should be the norm in the future. The Government’s Dementia Pathways Framework was created in 2013 to guide the health sector to create better pathways, ensuring they are supported in their journey living with dementia.”

“There are also practical things we can do – encouraging employers to take a more active interest, improving the way we deliver care – but for each of these parts to create a bigger whole we need to change our very culture – the way we think, talk and behave about dementia.”



## The home

Supported by access to better services and access to carers at home, people living with dementia will be able to live in their own homes for longer.

# Workplaces: key to educating, promoting risk reduction and supporting families

**The workplace is an important setting in creating greater dementia awareness – from risk reduction and early detection to creating dementia inclusive communities and supporting those who are caring for people with dementia, or living with dementia themselves. Almost half of the world’s population is in employment, and people’s working lives are longer than ever before.**

By creating a culture of dementia awareness, employers can help tackle the stigma surrounding dementia and provide support for those who may be caring for loved ones with dementia. In England alone, carers spend 28 hours a week on average caring for someone with dementia. Over half (51%) are also working, spending an average of 18 hours a week caring on top of their jobs<sup>v</sup>.

Dr Adshead says: “Working adults aged between 40 and 60 often have to care for both their own children and elderly parents with little time to prioritise themselves or their own health. Employers have a vital role to play: workplace health programs can help to keep them healthy today and reduce their risk of developing NCDs in the future.”

Employers have a key role to play in integrating dementia awareness, education and risk reduction in the workplace. Professor Stokes says: “Action in the places where people live and work is where the future lies. The numbers of people who are and will be affected by dementia over the next 35 years are so great that health and care systems will only be able to address the bookends of diagnosis and care of the most vulnerable, because to do more is likely to be unaffordable.”



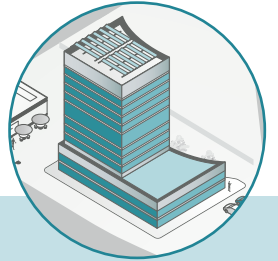
Raising dementia awareness and encouraging healthy lifestyles helps support people to age well and may help reduce their chances of developing dementia. Katie Dain, Executive Director of the NCD Alliance, comments: “Dementia and NCDs are collectively driven by the same shared risk factors and social determinants; experience the same challenges, myths and misconceptions; and demand similar approaches and solutions. Like for cancer, diabetes and heart disease, it can become second nature that ‘what’s good for your heart is also good for your brain’. With an ageing workforce and an increased awareness of the opportunity for dementia risk reduction in working age adults, healthy workplaces are a key lever to tackle dementia and other NCDs in the future”.

Education is important in creating dementia inclusive workplaces. Keith Oliver was diagnosed with early onset dementia in 2010, when he was working as a Primary School Head Teacher. Mr Oliver explains:

**“Dementia significantly affects the person diagnosed and those closest to them. It affects your ability to work, and in turn can lead to a sense of guilt – like you’re letting yourself and others down. Working is an important part of life and contributes to an overall feeling of self worth and identity. Education and tolerance are crucial to understanding these concerns and supporting people who are living and working with dementia.”**

Keith Oliver





Bupa has developed the 'Person First Pledge', a programme to increase peoples' understanding of dementia and help create a more dementia-inclusive society.

Person First Pledge is a self-directed 20 minute online course currently available in English and Spanish, with plans to develop further translations in late 2016/early 2017. It covers four areas: what dementia is, how to help someone live well with dementia, how you might be able to reduce the risk of getting it, and a personal pledge people can make. This pledge could be a commitment to reduce their risk factors, or something they will do for somebody else.

Commenting on the recent rollout of Person First Pledge in Spain, Dr Tomás says: "In Spain this has been an important tool in creating more awareness about what dementia is and what it is like to live with dementia. Our objective is to transform our people into active ambassadors for a dementia friendly society, to create dementia inclusive workplaces and communities, and to encourage people to take measures to reduce their risk of developing dementia. This will mean a radical change in peoples' understanding of dementia."

## The workplace

Employers will play a key role in integrating dementia awareness, education and risk reduction in the workplace. They will also create dementia-literate working environments that are able to respond to the needs of employees who are also caring for loved ones living with dementia.

We need to be prepared for dementia in the workplace, as more people are working for longer. Through more understanding and awareness, as well as adapting workplaces and design, we can help people with dementia to feel supported in the workplace and feel they can remain in the workforce for longer. It's clear that addressing the dementia challenge starts with education and risk reduction. It means changing both what we do and how we think about dementia.



# Environment and community: the need to understand dementia as a civic responsibility

**Thomas Bohlke, a Bupa Admiral Nurse and specially-trained dementia care practitioner supporting people living with dementia and their families in Scotland, believes that the lack of education and understanding is one of the biggest problems and needs to be addressed. He explains in the context of his work:**

“Admiral Nurses ensure that an experienced specialist is on hand and, by assessing personal situations, can take care of things there and then. We provide a truly personalised service. By bringing advice and emotional support to people living with dementia and their families when they need it, we can avoid many people having to go into residential care. We are also there for as long as required – this is unique.”

Bohlke also believes that this kind of approach works well for families who, contrary to popular belief, often don't see care of a loved one with dementia as a 'burden' that they want to be relieved of, even in the face of considerable difficulty. He comments:

**“Many family carers are saying they're happy to do the care and don't want to outsource it, but they need the support to be able to cope, including respite from care, to be able to continue. This is possible when specialist nurses put personal care plans together and work with relatives and carers to make the plan a reality.”**

Thomas Bohlke

For those who require residential care, rising expectations of standards and quality in care demonstrate the need for an informed, educated and supported workforce in care homes – a goal that Admiral Nurses are working towards.

“In 2030, today's innovations will be the norm,” says Bohlke. “The kind of work we now do in residential care homes in terms of workplace training and helping homes to analyse and improve their own practice using evidence – essentially taking a scientific approach to see what's working and needs work – will raise standards across the board. People working in care homes will be equipped with all the education and support they need to deliver the very best care.”

Apart from the lack of understanding and education, Prof. Stokes believes that another problem that needs to be addressed is the way the system is designed:

“The current system isn't working and it isn't what people want. The Alzheimer's Society in the UK reports that 80% of people in care homes have dementia or some form of memory problems<sup>vi</sup>, yet the way care is designed and funded, we only address dementia when we're at a crisis point. We could do much more to prevent and manage the early stages before people end up needing acute or long-stay care. However, with early intervention and care management not happening for most people, it is difficult to collect the evidence to demonstrate that this approach has both human and cost benefits. Instead it is seen as a leap of faith. As the population ages we need to ensure that we get to a better situation before we walk into a care crisis – right now it is a scandal that in many developed countries we diagnose dementia and then discharge.”



According to Prof. Stokes, formal care will continue to play a key role, but societal change will only come about by understanding dementia as a personal and civic responsibility. He describes this aspect as the ‘community wrap-around’:

“By ensuring good dementia awareness education at school, creating dementia-friendly communities and workplaces, and encouraging personal responsibility for reducing the risk of dementia, we may approach a situation where the value, involvement and support of people with dementia will have been transformed by 2030. It will mean raising the bar considerably in terms of what it means to be a dementia-informed society.”

## The school

Schools will deliver dementia education and begin at an early age, tackling stigma at grassroots level, creating a dementia-friendly generation.



## The role of technology

Assuming hearts and minds have been won, what about the role of technology in delivering a dementia ready society? Certainly technology can alleviate part of the problems already outlined. For example, once a care plan has been agreed for an individual that takes into account their life, their preferences and their carers' needs, web-based technology can allow it to be accessed by all healthcare professionals. Selected information can be shared with community service providers such as cleaning and catering companies or even taxi firms. This would enable a future where a lack of information for people providing everyday services or simply 'not knowing' no longer impacts on the daily experiences and lifestyle of people living with dementia.

Technology can also help carers. As an example, in Spain, the Fundación Sanitas has developed 'Cuidar Bien' – a website which helps carers to take care of their own health so they are better able to take care of their loved one. It also provides advice on managing the different stages of the disease and a whole host of technical expertise from dementia experts.

In the future, technology will also make it easier to remain living at home, to do the shopping or even interface with a nurse or GP. In addition, the use of global positioning system (GPS) technology could also help monitor the movement of an individual and ensure they are free from harm.

There are already a number of trial GPS tracking systems operating in the UK, which help to balance the independence of people living with dementia with their safety. Most importantly, we should consider the scope of technology to evoke memories through music devices and to help bring people closer to their families again – the chance to work from home and to care and provide for a family – the solution that the 'sandwich generation' needs so desperately today.

Although technology may facilitate things in the future, "it will never replace people", Dr. Tomás says. Prof. Stokes adds: "Supporting people with dementia is all about human relationships". Something we must not forget as our approach to dementia evolves in the future."



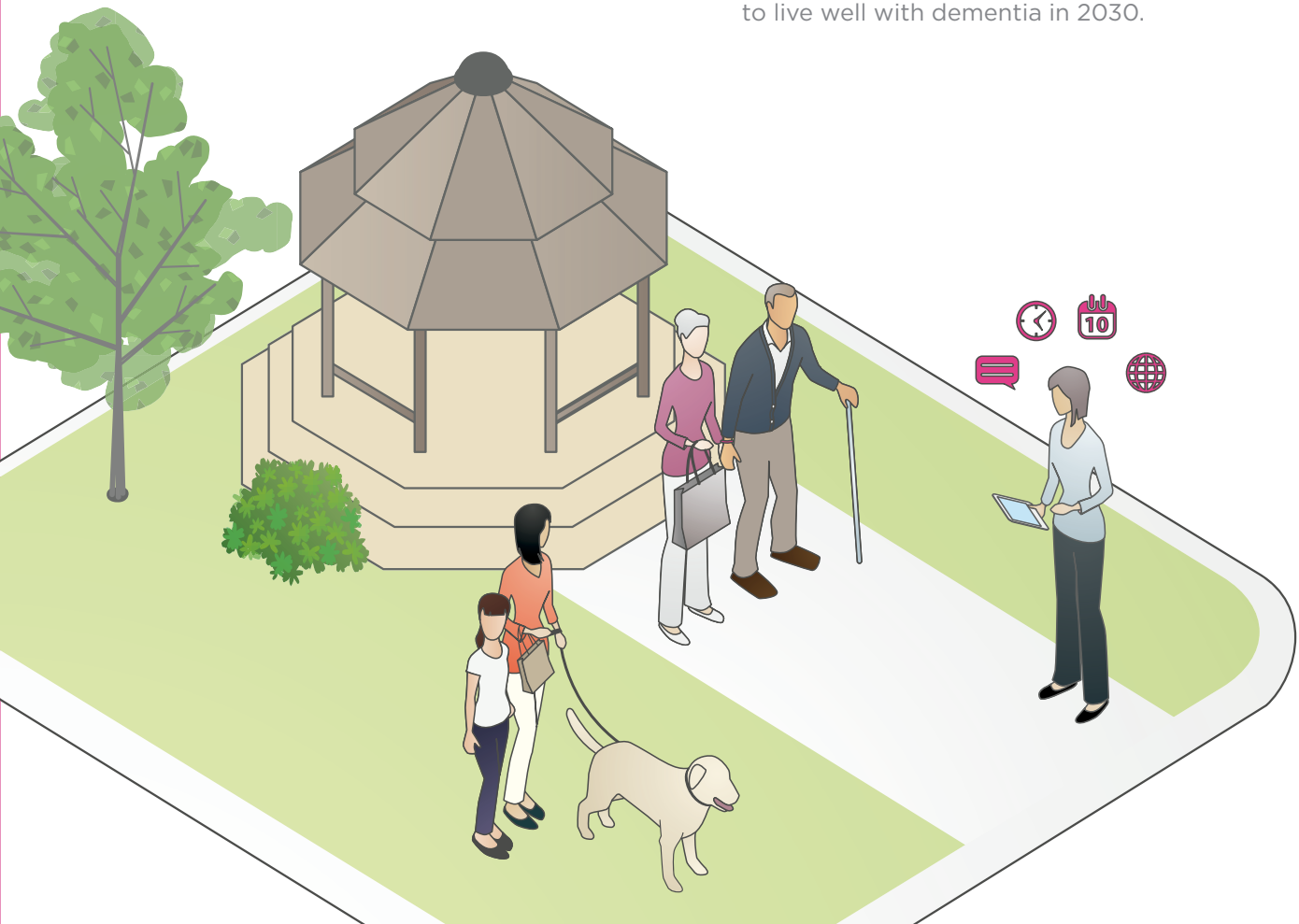


## Millions more people living well with dementia in 2030

Looking to the future, and to shape dementia strategies that will make a difference, commentators point to the importance of being ultra-realistic. To do this, we must take into account how the fabric of society is changing and how different things will also be in terms of social, economic and ethnic mix by 2030. Kate Emery, a Bupa care home manager in South London, points out that while the population of the home she manages currently comprises a generation of individuals who were born, raised and lived their lives in the local area, the future demographic will likely represent a multi-cultural population with very different origins and experiences. The same is true of those who will care for them. With dementia being as ‘individual as the person concerned’ ask more of all of us to be dementia friendly in our lives, communities and environments.

By 2030, living well with dementia can be a reality, but only if governments and societies make it an urgent priority. Survey data reveals<sup>vii</sup> that people over 55 are more concerned about dementia than cancer, heart disease or stroke. Prof. Stokes says: “Risk awareness and action has to start during people’s 30s or early 40s. People who are living with dementia in their 70s and 80s would already have the pathology in their brains from their mid 40s, so the adoption of health and lifestyle advice at an early stage will be critical and should be a cornerstone of public policy.”

Meeting these challenges will require collaboration and sharing of learnings on a global scale to create change, and quickly – 2030 is only 15 years away. But it is possible. With continued and enhanced political support, evolution of care offerings, collaboration between organisations, and a little more thought, awareness and understanding from each of us, millions more people may be able to live well with dementia in 2030.



## References

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- iv The Alzheimer's Association <http://www.alz.org/what-is-dementia.asp>
- v <http://www.cebr.com/reports/cost-of-dementia-to-business/>
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