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SCHOOL OF SOCIAL POLICY



# UNDERSTANDING AND RESPONDING TO THE NEEDS OF THE CARERS OF PEOPLE WITH DEMENTIA IN THE UK, THE US AND BEYOND

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## ABOUT THE AUTHORS

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## ABOUT THE SCHOOL OF SOCIAL POLICY

The mission of the School of Social Policy at the University of Birmingham is 'to understand the world – but also to change it'. This means generating new knowledge through high quality research, and using this as a starting point for making a practical difference in the real world (through our teaching, through professional training and CPD for managers and practitioners, through policy advice and work in front-line services, through raising public and media awareness and through working directly alongside local people and communities). In turning this mission into practice, we are proud of our many achievements, including running the UK's oldest social work training programme (dating back to 1908); our longstanding involvement in running the educational component of the multiple award-winning NHS Management Training Scheme; the relationships we have with local and national partners in the public and voluntary sectors; and our role as part of the consortium designing and delivering senior leaders programmes on behalf of the NHS Leadership Academy. More than three quarters of our research is rated as 'world leading' or 'internationally excellent' in terms of its rigour, significance and originality.

## ABOUT THE WALGREENS BOOTS ALLIANCE

The Walgreens Boots Alliance is the largest retail pharmacy, health and daily living destination across the US and Europe. Walgreens Boots Alliance and the companies in which it has equity method investments together have a presence in more than 25 countries and employ more than 385,000 people, with more than 13,200 stores and more than 390 distribution centres delivering to more than 230,000 pharmacies, doctors, health centres and hospitals each year. This paper was commissioned by Richard Ellis, Vice President, Corporate Social Responsibility.



# BACKGROUND AND INTRODUCTION

As the population ages, societies around the world are having to find new ways of responding to the rapidly growing number of people with dementia, and to the needs of carers (people who provide unpaid care and support for disabled or older people). While carers can be young or old, many will be of working age, with some people supporting both their own children and their parents or parents-in-law (the so-called 'sandwich generation'). This places significant challenges on individuals and families; welfare services (how best to support people with dementia, as well as the friends, neighbours or family members who care for them); and businesses (how to retain and support skilled and experienced workers who may be finding it difficult to combine both work and caring).

According to Alzheimer's Disease International (ADI):

*"Someone in the world develops dementia every 3 seconds. There were an estimated 46.8 million people worldwide living with dementia in 2015 and this number is believed to be close to 50 million people in 2017. This number will almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050. Much of the increase will be in developing countries. Already 58% of people with dementia live in low and middle income countries, but by 2050 this will rise to 68%. The fastest growth in the elderly population is taking place in China, India, and their south Asian and western Pacific neighbours... The total estimated worldwide cost of dementia is US\$ 818 billion in 2015, which represents 1.09% of global GDP. By 2018, the global cost of dementia will rise above a US\$ trillion. This figure includes costs attributed to informal care (unpaid care provided by family and others), direct costs of social care (provided by community care professionals, and in residential home settings) and the direct costs of medical care (the costs of treating dementia and other conditions in primary and secondary care).... **[If global dementia care were a country, it would be the 18th largest economy in the world. The annual costs exceed the market values of companies such as Apple (US \$742 billion) and Google (US \$368 billion)."***

In the UK, it is estimated that one in three people will care for a person with dementia in their lifetime. As a recent review (Newbrunner et al., 2013, p.12) has suggested:

*"There are around 800,000 people with dementia in the UK and an estimated 670,000 family and friends acting as primary carers to someone with dementia. The current financial cost of dementia to the NHS, local authorities and families is £23bn a year; this is expected to grow to £27bn by 2018..."*

*Caring for someone with dementia can be different from caring for people affected by other types of illness or disability, because of the complex, unpredictable and progressive nature of the illness. Carers of people with dementia are likely to have higher than normal levels of stress, and report higher levels of depression than carers of other older people... Consequently, carers' needs for practical and emotional support to relieve the emotional stress of caring are especially high..."*

*Carers of people with dementia are often in their 50s or 60s and are balancing work and caring for parents and others... or they are older people caring for a partner. Research (over more than 20 years) has clearly shown that caring has an adverse effect on carers' own physical and emotional health... Yet the more demanding the care is, the less likely it is that carers will have time to look after, or seek help in relation to, their own health."*

Other common themes from the literature include the financial impact if carers have to give up work, the emotional impact on family relationships, and feelings of isolation, exhaustion and/or helplessness - as well as a series of practical, financial and legal issues which can arise when caring for someone with dementia. Given current demographic pressures, this is an issue that already affects a substantial number of people, but one which will be of increasing significance to societies, governments, families and businesses around the globe.

# METHODS AND APPROACH

Against this background, the Walgreens Boots Alliance has commissioned the University of Birmingham's School of Social Policy to conduct a rapid review of the literature on the experiences of the carers of people with dementia, supplemented by a series of interviews with key respondents (policy makers, welfare services, charities and employers) in a number of different national contexts (see Appendix A for further details). This builds on previous work which Walgreens Boots has undertaken training its pharmacists to identify carers of people with dementia from the medication they may be collecting on behalf of the person they care for, and provide practical information and advice (see 'Recommendations' section below).

In particular, this paper explores:

- Insights into the role and experience of carers in different national contexts
- Good practice examples of services, organisations and approaches which have sought to improve support to the carers of people with dementia
- Policy and practice recommendations for key stakeholders such as policy makers, welfare services and employers

Given the traditional focus of Walgreens Boots in the US and the UK (and given very different policy contexts and welfare mixes), the review focuses on these two countries, with additional insights from other countries prominent in the literature and representing different welfare regimes. After searching the literature and following dialogue with UK and US respondents, this includes:

- Norway (as an example of developments in a Scandinavian system with a comprehensive welfare state, an emphasis on maximising labour market participation and a commitment to gender equality)
- Australia (as an example of an Australasian country with strong links to the UK)
- South Africa (as an example of an African country with a younger population but a growing recognition of future needs as the population ages, as well as challenges with HIV-associated dementia)

Throughout the paper, there is an overarching question about the extent to which different countries are ready for the implications of the demographic changes they face, and there are regular textboxes which pose questions to government, to employers, to health and social care, and to broader society to help them reflect on key themes.

## Reflection (for society, government, employers, and health and social care)

How ready are we as a society for the demographic changes we face?

# NATIONAL PROFILES

To set the scene, some brief facts and figures are presented in tables below to give an indication of the number and experience of carers (and of the carers of people with dementia) in each national context. However, beyond these statistics, our participants and the broader literature were clear that carers' experiences and the support available are very context-specific – both in terms of key differences in national legislation/health and care systems, but also in terms of different cultural and social attitudes to issues of care, family, gender and the role of the state in meeting welfare needs. Concentrating on just two of our countries, participants told us that carers of people with dementia in the UK often feel unsupported and taken for granted, and that formal health and social services are not as good at understanding dementia or at recognising and valuing carers as they should be.

However, they also acknowledged that – however imperfect and under-resourced our health and social services – there have been growing legal rights for carers over time, greater support available and greater recognition of the needs and rights of carers (albeit with much more still needing to be done). In contrast, participants from the US described a situation in which there is minimal state support and a belief that individuals should be primarily responsible for themselves and their families. This differed from a Scandinavian belief in the importance of a strong state, high taxes, high quality welfare services and equality between men and women – with different beliefs and approaches again in Australia and South Africa. While different countries make different political and economic choices, the point here is that what is possible and what may work in one setting might easily be very different to what may be feasible or effective in another country – and understanding these contextual differences is crucial for any attempt to influence national policy and practice.

|                                       | UK   |
|---------------------------------------|--|
| <b>Carers in the UK</b>               | <ul style="list-style-type: none"> <li>• 1 in 8 adults (around 6.5 million people) are carers (this will increase to 9 million by 2037). 58% are women and 42% are men</li> <li>• Carers save the economy £132 billion per year</li> <li>• Over 3 million people juggle care with work, but 1 in 5 carers are forced to give up work altogether</li> <li>• People providing high levels of care are twice as likely to be permanently sick or disabled</li> <li>• Over 1.3 million people provide over 50 hours of care per week</li> <li>• (<a href="http://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures">www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures</a>)</li> </ul>  |
| <b>Carers of people with dementia</b> | <ul style="list-style-type: none"> <li>• There are 700,000 carers for the 850,000 people living with dementia in the UK</li> <li>• 150,000 years were spent caring for people with dementia in 2013 or 1,340,000,000 hours</li> <li>• In 2016/17, 30% of carers for people with dementia had been doing so for between 5 and 10 years and 22% for over 10 years</li> <li>• 60-70% of carers for people with dementia are women</li> <li>• 63% of carers for people with dementia are retired while 18% are in paid work; 15% of dementia carers say they are not in work because of their caring responsibilities</li> <li>• (<a href="http://www.dementiastatistics.org/statistics/impact-on-carers/">www.dementiastatistics.org/statistics/impact-on-carers/</a>)</li> </ul> |

## Reflection (for society and government)

Different countries make different choices about what kind of support is provided and by whom. What kind of a life do we want to have together, and what does this mean for how we organise care and support?

|                                       | US  |                                       | Norway  |
|---------------------------------------|---|---------------------------------------|---|
| <b>Carers in the US</b>               | <ul style="list-style-type: none"> <li>• There are approximately 43.5 million caregivers in the US</li> <li>• About 15.7 million adult family caregivers care for someone who has Alzheimer's disease or other dementia</li> <li>• The value of services provided by informal caregivers has an estimated economic value of \$470 billion (2013). This exceeds the value of paid home care and total Medicaid spending in the same year, and nearly matched the value of the sales of the world's largest company, Wal-Mart (\$477 billion)</li> <li>• Upwards of 75% of all caregivers are female, and may spend as much as 50% more time providing care than males</li> <li>• Family caregivers spend an average of 24.4 hours per week providing care. Nearly 1 in 4 caregivers spends 41 hours or more per week providing care</li> </ul> <p><a href="http://www.caregiver.org/caregiver-statistics-demographics">www.caregiver.org/caregiver-statistics-demographics</a></p>   | <b>Carers in Norway</b>               | <ul style="list-style-type: none"> <li>• In Norway, one in six people (about 15% of the adult population) regularly provide unpaid care to older, sick or disabled people</li> <li>• Caring is most prevalent amongst people aged 45-66, with 20% of people in this age group provided regular unpaid care</li> <li>• The number of carers is approximately the same for men and women</li> <li>• Many carers also work – 15% of full-time workers and 20% of part-time workers are carers</li> </ul> <p><a href="http://www.ssb.no/en/helse/artikler-og-publikasjoner/middle-aged-perform-most-unpaid-welfare-work">www.ssb.no/en/helse/artikler-og-publikasjoner/middle-aged-perform-most-unpaid-welfare-work</a></p>   |
| <b>Carers of people with dementia</b> | <ul style="list-style-type: none"> <li>• 16.1 million Americans provide unpaid care for people with dementia, providing 18.4 billion hours of care, valued at \$232 billion</li> <li>• Eighty-three percent of the help provided to older adults in the US comes from family members, friends or other unpaid caregivers. Nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia</li> <li>• About one in three caregivers (34%) is aged 65 or older</li> <li>• Approximately two-thirds of caregivers are women; over one-third of dementia caregivers are daughters</li> <li>• Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers (caring for an older parent and a child under 18)</li> <li>• Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.</li> <li>• Of the total lifetime cost of caring for someone with dementia, 70% is borne by families - either through out-of-pocket health and long-term care expenses or from the value of unpaid care</li> </ul> <p><a href="http://www.alz.org/facts/">www.alz.org/facts/</a></p> | <b>Carers of people with dementia</b> | <ul style="list-style-type: none"> <li>• Alzheimer Europe has estimated that there over 77,000 people with dementia in Norway in 2012. Over 80% of those living in nursing homes and over 40% of people over 70 who receive home care services have some form of dementia</li> <li>• Over 4,000 people under 65 may have dementia</li> <li>• The average cost to society of a person with dementia is NOK 360,000 a year (total costs could therefore amount to almost NOK 30 billion a year)</li> <li>• During the last month prior to admission to a nursing home, family members spend around 160 hours caring for the person, while over the same period only about 16 hours on average are spent by home care nurses and one to two hours by home helps</li> <li>• The Norwegian Ministry of Health and Care Services estimates that the number of people with dementia may double by 2040, with significant implications for health and social care, the design of the physical environment, and relationships with families and the voluntary sector</li> </ul> <p><a href="http://bit.ly/regjeringen12">http://bit.ly/regjeringen12</a></p> |

|                                       | Australia  |
|---------------------------------------|--|
| <b>Carers in Australia</b>            | <ul style="list-style-type: none"> <li>• In 2015, over 1 in 8 Australians (2.86 million people) were estimated to be providing informal care</li> <li>• 825,000 informal carers are 'primary carers', people who provide the majority of the recipient's care</li> <li>• The majority of informal carers are female and predominantly fall within the age range of 25-64 years</li> <li>• Informal carers provided an estimated 1.9 billion hours of care in 2015 (equivalent to each carer providing 673 hours per year or 13 hours per week)</li> <li>• If all hours of informal care provided in 2015 were replaced with services purchased from formal care providers, the replacement value of informal care would be \$60.3 billion (equivalent to 3.8% of Gross Domestic Product and 60% of the health and social work industry)</li> <li>• In the next ten years, the demand for informal care is set to significantly outstrip supply. According to Deloitte Access Economics (2015, p.iv), <i>"there is a strong case to consider the following suggestions as part of a concerted policy effort to reduce the carer deficit:</i> <ul style="list-style-type: none"> <li>- <i>greater flexibility in working arrangements to accommodate workers' caring responsibilities and employment preferences;</i></li> <li>- <i>improvements in access to, and awareness of, carer support services such as respite care to encourage service utilisation and alleviate the impact of caring;</i></li> <li>- <i>further investigation of carer perceptions of the costs and quality of formal care to encourage an optimal mix of formal and informal care provision; and</i></li> <li>- <i>adapting the formal care sector to meet the needs of older Australians from diverse backgrounds to improve the flexibility of care options."</i></li> </ul> </li> </ul> <p>(all statistics from Deloitte Access Economics, 2015)</p>   |
| <b>Carers of people with dementia</b> | <ul style="list-style-type: none"> <li>• Dementia Australia estimates that there are 413,106 Australians living with dementia and around 291,163 Australians involved in their care. Three in 10 people over the age of 85 and almost one in 10 people over 65 have dementia. In 2018, there is an estimated 26,443 people with younger onset dementia, expected to rise to 29,375 people by 2025 and 42,252 people by 2056 (<a href="https://carers.dementia.org.au/">https://carers.dementia.org.au/</a>)</li> <li>• According to the Australian Institute of Health and Welfare (2012, p.117), about 9 in 10 (92%) people with dementia living in the community were receiving care from one or more carers (in 2009)</li> <li>• Estimates suggest that around 200,000 Australians were carers of a person with dementia living in the community in 2011</li> <li>• About two-thirds of carers of people with dementia living in the community were women, and roughly half were aged 65 and over</li> <li>• Around 42% of main carers of a person with dementia were the spouse/partner of the care recipient and 44% were the son or daughter</li> <li>• Co-resident primary carers of people with dementia were more likely than all co-resident primary carers to: <ul style="list-style-type: none"> <li>– be providing continuous, rather than episodic, care (94% and 72% respectively)</li> <li>– be providing 40 or more hours of care per week (81% and 42%)</li> <li>– report at least one of four negative consequences (such as feeling weary or frequently feeling worried) due to their role as carer (57% and 48%)</li> <li>– have their sleep interrupted either frequently or occasionally due to their caring role (66% and 49%)</li> <li>– need additional support or an improvement in their situation (52% and 33%), with the greatest area of need for carers of people with dementia being more respite care</li> </ul> </li> </ul> <p><a href="http://www.aihw.gov.au/reports/dementia/dementia-in-australia/contents/table-of-contents">www.aihw.gov.au/reports/dementia/dementia-in-australia/contents/table-of-contents</a></p> |

|                                       | South Africa  |
|---------------------------------------|---|
| <b>Carers in South Africa</b>         | <ul style="list-style-type: none"> <li>• It is difficult to obtain accurate and easily accessible data on carers in South Africa</li> <li>• However, broader studies of East and Southern Africa suggest that (Schatz and Seeley, 2015, abstract): <i>“An estimated 58 million persons aged 60-plus live in sub-Saharan Africa; by 2050 that number will rise sharply to 215 million. Older Africans traditionally get care in their old age from the middle generation. But in East and Southern Africa, HIV has hollowed out that generation, leaving many older persons to provide care for their children's children without someone to care for him or herself in old age. Simultaneously, the burden of disease among older persons is changing in this region. The result is a growing care deficit.”</i></li> </ul>   |
| <b>Carers of people with dementia</b> | <ul style="list-style-type: none"> <li>• Alzheimer's South Africa estimates that approximately 750,000 people have dementia. In a very different system to the UK, “Alzheimer's disease threatens to bankrupt families, with escalating medication costs and no support to pay for either day or full time care” (<a href="http://alzheimersinaction.co.za">http://alzheimersinaction.co.za</a>)</li> <li>• Research from the University of the Free State has suggested that the incidence of dementia may be much higher than previously expected (rates were incorrectly assumed to be lower in urban black communities, and this does not appear to be the case)</li> <li>• Many health services are focused on meeting the needs of people with HIV/Aids or with TB, with less recognition of the needs of people with dementia or their families</li> <li>• High mortality rates from these diseases means that many older people with dementia are left without families to care for them, and/or that an increasing amount of childcare is falling on grandparents in situations where the children's parents have died (<a href="http://www.ufs.ac.za/templates/archive.aspx?news=1871&amp;cat=1">www.ufs.ac.za/templates/archive.aspx?news=1871&amp;cat=1</a>)</li> <li>• There are significant difficulties meeting the needs of people in rural areas, and of responding to the needs of rapid urbanisation</li> <li>• There are increasing numbers of people with HIV-associated dementia (for a brief overview of dementia in South Africa, see de Jager et al., 2015)</li> </ul> |



# INSIGHTS FROM THE LITERATURE

There is a broad literature exploring the needs and experiences of carers of people with dementia and evaluating the available support. From a rapid review of the existing empirical research and previous systematic reviews, a number of themes emerged. The first part of this review explores the needs of carers identified in the literature, which include emotional well-being, physical health, social relationships and practical needs, with a significant amount of overlap between these categories. The second part focuses on support for carers, and looks at the support available, what makes it effective and the barriers carers experience in accessing timely and appropriate services.

This review includes research from Europe, the Americas, Australia, East Asia, India and Iran. Despite the diversity of these national contexts, welfare systems and cultural differences, there were marked similarities in the reported needs and experiences of carers (Dourado et al., 2017; Schneider et al., 1999).

## 1. Carer Needs

**Emotional needs:** the emotional impact of providing care for a partner, parent or other family member is consistently highlighted in the research. In addition to depressive symptoms, carers in many studies expressed feelings of grief, loss, isolation, frustration, uncertainty, stress, fears about the future, and a low sense of self-esteem and self-efficacy (Yu et al., 2016; Cabote et al., 2015; Yong and Price, 2014; Gruffydd and Randall, 2006; Chou et al., 1999). Carers also reported feeling overwhelmed, helpless or abandoned by being left to care for their family member without support, training or resources (Casadro et al., 2015; Samuelsson et al., 2001; Lilly et al., 2012). O'Dwyer et al (2013), looking at suicidal ideation among carers, found this risk to be exacerbated by existing mental or physical health conditions in the carer and by conflict with family members or professionals, which can become an additional tension carers may need to manage.

**Physical well-being:** the emotional demands of caregiving can also impact on physical well-being. Horner et al (2012) found that carers reported a lower health status than the general population, and highlighted symptoms such as insomnia, fatigue and pain.

The physical demands of caring can also take their toll on the health of those undertaking this role. The unpredictability of care needs can make it difficult for carers to maintain a routine, particularly one which includes time for exercise, self-care activities and pursuing their own interests (Moreira Rodrigues, 2017; Tatangelo et al., 2018). Sleep disturbances were commonly experienced by carers due to safety concerns about their family member during the night and anxieties about their caring role (Simpson and Carter, 2013). Health impacts were seen to increase as the condition of the person with dementia progressed (Zverova, 2012).

**Social needs:** at the same time as carers are dealing with the emotional and practical demands of their caregiving role, they also face a narrowing of their social networks. For people caring for their partner, where they may previously have shared household tasks and talked through emotional difficulties with their partner, they are now dealing with these single-handedly in addition to their caring responsibilities (Schneider et al., 1999). Wang et al (2017) describe this as an unbalanced intimacy in which the carer increasingly compensates for their partner's growing dependency. This is not to say that it is always the loss of a positive relationship – research has shown that the quality of relationship prior to the onset of dementia can have a lasting impact on the carer's well-being (Quinn et al., 2009; Samuelsson et al., 2001).

Dealing with behavioural disturbances and personality change is a particularly common cause of distress for carers, and was the most challenging adjustment to make for many (Millenaar et al., 2016; Shaji et al., 2003; Yamamoto-Mitani et al., 2000). Concerns about the unpredictability of the person's behaviour can lead carers to avoid social situations where this could prove difficult to manage. Similarly, the stigma of dementia can prompt carers to seek to hide the severity of their family member's condition as a way of protecting their dignity (Boots et al., 2015). This limits the carer's ability to maintain existing social networks, as well as limiting their opportunities to engage with new people and social activities, which exacerbates feelings of isolation (Sanders et al., 2008).

**Practical needs:** carers are increasingly expected to carry out a wide range of tasks for the person they are supporting, including personal care, managing medication and health monitoring. Lee et al (2016) found that family caregivers in the US felt untrained and underprepared for the roles they were undertaking. Older adults who are caring for their partners may be required to undertake physically demanding tasks despite their own physical frailty due to the lack of available support with hands-on care (Pickard and Glendinning, 2001).

While dementia most commonly affects older people, many are cared for by their adult children or other younger relatives. Pressures can be particularly intense for the so-called 'sandwich generation', where someone who is middle-aged may be balancing caring for a parent with dementia with raising children and maintaining paid employment (Vreugdenhil, 2014). This exacerbates the financial impact of being a carer in addition to the social and emotional demands of the role (O'Brien et al., 2013).

#### Reflection (for government and for health and social care)

To what extent do our services meet the practical, emotional, social and health needs of carers?

Is support sensitive to the potentially different needs and experiences of younger carers, the so-called 'sandwich' generation and carers whose partners have dementia?

## 2. Carer Support

**Available support:** the existing literature spans a wide range of programmes and interventions aimed at supporting people with dementia and their carers. Meaningful comparison between the different sources of support is difficult due to the differences in aims, target groups and outcome measures, but it is possible to identify a number of common characteristics that carers found useful, and a range of barriers which limit the accessibility and responsiveness of the support on offer. The models of support set out in the articles included in this review can be divided into four main categories of: peer support; skills-based support; functional support; and activity-based support.

Support groups, whether delivered in person, online or by telephone conference, tend to be based on a psychoeducational model which aims to encourage group members to share knowledge and experiences with peers, sometimes with input from professionals (Lee and Yim, 2013; Grassel et al., 2010). Skills-based services provide structured techniques to support carer well-being and resilience, such as meditation and stress management (Thomas et al., 2017; Mitchell, 2000). Functional support such as assistive technologies and short breaks aim to provide practical help to people with dementia and offer carers a break from the physical and emotional labour of care (Alwin et al., 2013; Tretteteig et al., 2017). Examples of activity-based support include more structured creative arts and drama programmes, as well as more informal projects such as dementia cafés (Greenwood et al., 2017).

**Effectiveness of support:** a key message from the research is that there is no one solution to meet the needs of all carers (Sommerlad et al., 2014; Johannessen et al., 2015). Thomas et al (2017) emphasise the value of multi-component interventions in responding to the diverse needs of people with dementia and their carers. Within this approach, the most valuable elements for carers include services that develop resilience, address isolation and enable peer support in a non-judgmental environment (Colvez et al., 2002; Thomas et al., 2017). Knowing that the person they cared for was close by and well looked after also enabled carers to participate fully in any intervention (Pienaar and Reynolds, 2015). A number of studies found that coping strategies were more effective when they were problem-focused rather than emotion-focused, and this was associated with increased resilience (Thinnes and Padilla, 2011; Papastavrou et al., 2007).

#### Reflection (for government and for health and social care)

Is there a spectrum of support available to meet the diverse needs of people with dementia and carers in different contexts? Do carers say that we have the right mix of peer support, skills-based support, functional support and activity-based support?

### 3. Barriers to accessing services

Three broad themes were identified as barriers for carers to accessing appropriate support: lack of knowledge of trustworthy services; services not being responsive to carer needs; and carers not identifying with the 'carer' label.

**Lack of information:** carers looked for advice, information and support from a range of sources, but found it difficult to evaluate the usefulness of this information and identify trustworthy services (Macleod et al., 2017). Peterson et al (2016; see also Lee, 2016) found that carers looked to their primary care provider to endorse particular sources of support, and continued to place a high value on this validation even when the responses they received from their provider were limited. For people from minority ethnic communities (Lawrence et al., 2008; Gelman, 2010) and LGBT people (Barnett et al., 2015; Price, 2010) in particular, distrust of services can be a key barrier based on negative past experiences or fear of discrimination. This research emphasises the value of a relationship with a trusted professional as a medium for increasing carer engagement with support programmes.

**Responsiveness of services:** the needs of carers change throughout their caring journey, and it is important that the support they need is there for them at the right time (Lin et al., 2011). It can be difficult for carers to anticipate their needs in advance, as there tends to be a gradual build-up of symptoms in the person they are supporting rather than a 'threshold moment' that leads them to seek help (Lee et al., 2016). Consequently, information on likely support needs might come from those further ahead in the care trajectory to inform early intervention programmes for newer carers (Boot et al., 2015). As well as time-responsive support, Blackstock et al (2006) emphasise the importance of services that recognise the spatial context of a carer's experience. In rural areas in particular, isolation may be heightened and service delivery can be challenging (Morgan et al., 2002). Thinnies and Padilla (2011) suggest that technology-enabled interventions can help to overcome some of these barriers, but it is important to evaluate the impact of this method of delivery on carer well-being.

**'Carer' identity:** many of those fulfilling a caregiving role struggled to identify with the label of 'carer', and feared the loss of their own self-identity (Kim et al., 2016). This was particularly the case for those who were caring for a spouse or partner, who often viewed caregiving as a continuation of the spousal role. As a result, carers may not recognise that they are eligible for support in their caring role and may be reluctant to undertake training or other, more 'professionalised' elements of support. In the UK context, Lawrence et al (2008) highlight the impact on caregiving attitudes of cultural beliefs about caregiving as natural, expected and virtuous, which may be particularly prevalent in South Asian communities but less so among Black Caribbean carers and even less so among those of White British origin. In some contexts there was an expectation that particular family members would take on the caring role, often driven by gender and social norms (Casado et al., 2015). In India, for example, Shaji et al (2003) found that the majority of carers they interviewed were young women who were often caring for their mothers-in-law. This perception of caregiving as a natural and expected part of family life rather than an additional and challenging task can serve as a barrier to accessing support, and can increase feelings of guilt if care arrangements break down.

Overcoming these issues is not easy. Identifying as a 'carer' is a prerequisite for accessing support, but this can be hard for many carers due to cultural expectations, fear of loss of self-identity, and difficulties coming to terms with their family member's condition (Lee et al., 2016; Lockeridge and Simpson, 2013). While the peer support element of carer groups can help carers come to terms with their role and identity, Ismail and Mackenzie (2003) found that support groups assembled around cultural identity could also reinforce cultural norms about family duty and exacerbate feelings of shame around seeking outside help.

#### Reflection (for society, government, and health and social care)

Identifying as a 'carer' is often a prerequisite for accessing support, so how do we help people to understand that these services might be for them (if they don't perceive themselves as 'a carer'?) How can we do this without people losing other aspects of their identity? How can we question our assumptions about care, so that we expose underlying cultural expectations of care as 'natural' and about who 'should' care?

# STAKEHOLDER INTERVIEWS

In order to develop further insights into the global picture of carers for people with dementia, interviews were conducted with 15 key stakeholders from the UK, North America, Australia, Norway and South Africa. Their expertise spanned a range of disciplines and specialisms, including carer support, carer-led organisations, advocacy, social work, medicine and research. The interviews confirmed many of the findings from the literature review, but also highlighted additional factors which impact on the lives of carers. Many of the themes which emerged were common to most countries, but there were some important ways in which different national contexts presented specific challenges and responses to meeting the needs of carers.

The themes from the interviews fell within three broad categories: the needs of carers of people with dementia; current sources of support and the extent to which they are responsive to carers' needs; and good practice examples identified by participants. Participants identified dementia as a condition of increasing significance due to ageing populations across much of the world and the lack of current breakthroughs in treatment. Across all countries, services were already seen as underfunded and inconsistently provided, and participants highlighted demographic change as potentially exacerbating these challenges.

## 1. Carer Needs

Stakeholder interviews highlighted the need for carers to have consistent engagement with some sort of supportive system, so that they know where they can seek support, are able to build up a positive working relationship, and do not have to keep providing the same information again and again. The support that is available often tends to be short-term or issue-specific, whereas what is needed is long-term engagement that adapts to different stages of the caring journey, spanning from the pre-diagnostic phase, when the first signs of an issue are seen, right up until 6-12 months after the death of a family member with dementia.

**Emotional needs:** carers may struggle with different emotional needs as their family member's condition deteriorates, including a sense of helplessness,

isolation and grief. Carers experiencing a bereavement may also feel a sense of ambiguity that is difficult for others to understand (grieving for a deceased family member, but also feel incredibly guilty if part of them is also a little bit relieved that their caring responsibilities have ended). Similarly, spouses or children of people with dementia may go through a grieving process while their partner or parent is still alive. With younger carers in particular, one participant highlighted the sense of loss of an imagined future in which they had expected their parent or grandparent to play a role:

*"They say, I know my mother or father may not be there on days like my graduation, my wedding day, or the birth of my child – they may be there physically, but also not there." (Researcher, UK)*

Adjusting to this sense of loss can require support around grief and resilience to process the tensions between carers' previous and current expectations for their lives. There may also be an initial process of denial, and while this can be an important defence mechanism, it can also prevent carers from accessing the support available if it persists.

### Reflection (for health and social care)

Is support available over time and in a way which can adapt to changing or fluctuating circumstances?

Does it meet emotional as well as practical needs?

**Stigma and neglect of carers:** the stigma faced by people with dementia can also be felt by their carers, which can result in carers trying to hide the person's illness in order to protect them and the wider family from the social consequences. A participant in South Africa noted that this can also be seen among health professionals, who may minimise the diagnosis by referring to "mild forgetfulness" or link it to normative ageing processes rather than clearly explaining the symptoms and trajectory of dementia. Carers' social circles often begin to shrink as they stop taking part in activities they previously enjoyed, and begin to limit their outings to avoid having to deal with behavioural challenges in public.



As one male spousal carer said to a participant:

*"You soon know who your friends are when your wife has got dementia."* (Academic, Australia)

The wider community is also often unresponsive to the needs of people with dementia and their carers, which further increases social isolation. Even where an activity may be accessible to someone with dementia, there may not be any dementia-friendly options for transport. Participants raised the crucial importance of people in public services, places of worship and other community settings having the skills to interact with people with dementia and their carers.

With the dominant focus on the person with dementia, the needs and experiences of carers can be minimised or overlooked. Older carers in particular may have their own health problems, which can be exacerbated by their caring demands. Some respondents felt that policymakers have begun to pay more attention to the needs of carers of working age, seemingly due to the impact of their loss from the workforce, but that older carers who have retired can sometimes be overlooked.

#### Reflection (for society)

Given the demographic changes quoted at the start of this policy paper, dementia is a common experience across the world. Why do carers still feel so much stigma, and what can we all do to make this a normal, everyday topic of conversation, and to prevent social isolation?

**Relationships:** the importance of relationships emerged as a key theme in the interviews. While some people with dementia are living alone, for many there is a close and two-way relationship between the person being cared for and the carer, and support from carers plays a pivotal role in how long people can remain living in their own home. The quality of this relationship has a significant impact on the caring experience, and vice versa. Carers may be dealing with the loss of intimate relationships and the emotional availability of their partner, but may feel that they have to keep going out of a sense of duty or commitment. Caring for a family member can also provoke feelings of ambivalence due to previous experiences within the relationship.

One participant commented:

*"I don't use the term 'loved one' because this doesn't resonate with all carers. I avoid the term as it can add even more guilt"* (Carers organisation, US)

This can particularly be the case if someone is caring for a spouse or parent who has previously been abusive, and must adapt to the new dynamics of the relationship.

#### Reflection (for society and for health and social care)

Relationships are complex - should we avoid the term 'loved one' as too simplistic a way of describing this complexity?

A key emotion seems to be one of guilt - as a society, how/why do we make carers feel guilty, and how can we stop this?

**Information and advice:** getting the right information at the right time was seen as a significant need for carers for people with dementia. For participants, this meant information from authoritative sources, in a range of formats, and tailored to the relevant stage of their journey as a carer. Carers often say that they want information and advice, but rather than just a leaflet or website, they also want someone with knowledge and some level of power within the system who can help them make sense of the information provided. In the early stages of diagnosis in particular, carers may need realistic information and support to recognise the impact of the condition and find out about the changes people with dementia will go through, in terms of both cognitive abilities and daily living. The priority for many carers is to find effective treatment for their family member, without necessarily considering their own needs as a carer - and there is often a mistaken belief that symptoms can be improved or reversed.

**Financial needs:** access to early and meaningful financial advice is also a crucial element of support, but this is often not addressed until it becomes a problem, by which time the person being cared for may lack capacity to make financial decisions.

*"When a carer rings a bank to explain their father has dementia and the bank won't speak to them because they're not the account holder and there isn't a power of attorney, you know that something's wrong."*  
(Carers charity, UK)

In addition to daily living expenses, in many countries the costs of meeting health and social care needs are separated, and the services which could intervene early to prevent a future crisis are often not covered by the health service or by private insurance.

### Reflection (for employers)

Our workforces will be made up of lots of people who are 'carers' outside of work, some of whom may be facing competing demands which they are struggling to reconcile. How much do we understand about our employees, and what impact could a more supportive environment play in attracting and keeping good staff, reducing sickness, improving morale and boosting productivity? Do we need to consider carers' leave, flexible/home working and other forms of support?

For companies in the financial sector, is there a role we could play in providing greater financial advice and helping families to plan ahead (whether for our own workforce or for the public in general)?

## 2. Support services

Participants identified a range of support that is potentially available to carers, though this was seen as highly variable in terms of accessibility and responsiveness to specific needs. This included telephone helplines, support groups (both face-to-face and online), assistive technologies, training and peer mentoring. Access to services was also dependent on location, eligibility and local/national funding mechanisms.

**Assumptions about carers:** participants commented on the way in which the policy of enabling people to continue living in their homes for as long as possible, which has been widely adopted in a range of national contexts, is often seen as stemming from the wishes of people with dementia and their carers - but has also

become necessary as a way of managing capacity in residential homes and the increasing cost of formal service provision. One participant presented this in pragmatic terms:

*"In Norway, we have an ageing population, and there will not be enough nursing homes for all those who need them – there could be three generations of a family all needing aged care."* (Health professional, Norway)

As a result, a large number of people with dementia who may previously have gone into care homes are now living in the community. Alongside this, there has been an increasing expectation that family carers will spend more hours providing care and undertake more complex tasks that were previously carried out by health professionals, such as taking blood pressure, managing medication and monitoring drips. This increased 'professionalisation' of the role of family carers may provide them with the opportunity to develop their skills and knowledge, but at the same time it can serve to make them a part of the care workforce but without the rights and protections available to paid carers. For similar reasons, participants were divided on the value of skills training; while it was recognised that many carers wanted to develop their skills and confidence, there were also concerns that training could send the message that they are part of the care workforce rather than a family member with a pre-existing emotional connection to the person they are supporting.

### Reflection (for society and government)

Lots of our assumptions about health and social care have implications for carers. Policies of 'community care' or 'care closer to home' are laudable - but often assume that families will automatically be able to take on even more care. When services are less than optimal, the shortfall is usually made up by carers, who bear the brunt of this.

**Staff turnover:** the high turnover of paid care workers was identified as a barrier to continuity of care and the development of relationships of trust. Participants connected this to the low pay, precarity of employment and limited opportunities for career development in the sector. The money received by care workers was seen as insufficient to maintain their commitment to the

role, and the lack of specialised learning opportunities was seen as affecting their level of commitment and competence in their role.

**Support after diagnosis:** continuous and accessible service provision could also help address the ‘black hole’ faced by carers after the dementia diagnosis is first received; they may not generally need many practical services at this stage, but are likely to be adjusting to the change in their role and in their relationship with the person they are supporting and could greatly benefit from emotional support. While some participants felt that any professional had the potential to provide this continuity of support based on the relationship they were able to develop with the carer, others highlighted the value of highly trained and well-funded specialist practitioners fulfilling this role.

**Rurality, variation and access to specialist skills:** carers in remote or rural locations, particularly in Australia, Canada and South Africa, were seen as victims of the “tyranny of distance.” One participant described the “walk v work ratio” in South Africa as a way of conceptualising the time lost to travel in remote areas compared to the actual work that could be achieved on arrival. Even where the distances involved were more limited, such as in the UK, support was described as a “postcode lottery” in which there was wide variation in the level of services provided in each area. Similarly in Norway, services are funded at the local authority level, and in some areas with populations of a few thousand people, dementia care was not felt to receive sufficient priority.

This connects with the tension in participants’ responses between the value of generic and specialist services for people with dementia and their carers, due to the differing communities they might serve. Specialist services are able to bring particular skills and expertise, whereas generic support is more likely to reach a wider range of the population. In South Africa, a programme of community health workers was developed in response to the HIV/AIDS epidemic, and this is now being redirected towards dementia and other diagnoses. The programme was initially set up to improve access to services and to challenge stigma and discrimination within disadvantaged communities.

### Reflection (for health and social care)

What is the best balance to strike between specialist skills (these bring significant expertise, but can be expensive, hard to access and sometimes stigmatising) and more general support (less expert, but more easily available in local communities and possibly better at challenging stigma)?

A major issue raised by a number of participants was also the lack of co-ordination across services. Sometimes this was a feature of the system, such as in South Africa where clinical specialists are independently employed in separate services from hospital pharmacists and doctors, though some are seeking to tackle this by setting up practice clusters. In other contexts, such as the UK, there is a framework for sharing information in particular circumstances, but this does not always routinely happen.

**Defining success:** another issue identified by participants was that the support provided is almost exclusively to enable carers to continue caring and is evaluated in those terms. One UK participant identified an unmet need of permitting family carers to withdraw from care at an appropriate time rather going along with the default position of assuming the caring role will continue. Currently, this is often not allowed to happen, and where carers report exhaustion or depressive symptoms, they are offered support to ‘build their resilience’ rather than a frank conversation about what is manageable for them.

The way that services are evaluated can also increase barriers to effective support for carers. For example, carers may benefit from the effects of interventions that are intended to help people with dementia, but if these are measured solely in terms of impact on that person, then the positive benefit to the carer will be lost. In addition, the criteria for outcomes against which services are evaluated can often be unrealistic, inappropriate or too demanding, and can stifle innovation by trying to minimise risk. Where there may be an unplanned positive outcome, such as an improvement in carer well-being, this may not be captured in an evaluation based on a pre-set framework.

### Reflection (for society and government)

The success of services should be based on the quality of life of the person with dementia and those caring for them – not simply on whether carers continue to care. Service evaluations should also include the impact on carers – a policy which is seen as ‘cost neutral’ could be code for not costing government more money (but not recognising extra costs and burdens placed on carers).

**Diversity:** one assumption underlying much of the literature and discourse around carers for people with dementia is that both the person with dementia and their carer are likely to be older people in a spousal relationship. This is often the case, but not exclusively, and this can result in the particular experiences and needs of younger carers being overlooked. For example, access to employment for both people with dementia and their carers came up frequently among participants, particularly in relation to younger carers, or those caring for a person with younger-onset dementia. Many people who are diagnosed at an earlier stage in their illness want to stay in employment, but need support from employers, colleagues and carers to enable them to do so. Similarly for carers, those of working age are keen to remain in the job market, often out of necessity, but also to maintain relationships and social contact outside the house. This can have an impact on who takes on the caring role, particularly in contexts of high unemployment. In South Africa, for example, where approximately half of young people aged 15-24 are unemployed, caring responsibilities are likely to fall on those who have less access to the labour market, particularly women and young people, which can then have a knock-on effect on their future life chances.

Young people who take on the role of carer are often in homes which are more socio-economically deprived, and may be from one-parent households, or from two-parent homes where the other parent needs to work to support the family financially. This can mean that, alongside their caring responsibilities, young carers may be having to negotiate emerging adulthood on their own, without being able to call on their parent to work through this period of their life and support them with making important decisions. As young people move

### Reflection (for employers)

Do you know how many of your staff are carers, and the impact this has on their work and their lives? Are there competitive advantages in being a better employer for carers? Do the demographic changes summarised in this paper mean that all future recruitment and HR strategies will have to engage meaningfully with issues of care if we want to have any kind of workforce at all? Is support for carers an ‘optional extra’ or is it fundamental to everything we do?

Just as many of our staff will be carers, so too will our customers. To what extent are we mindful of this when we develop and promote our products and services? As but two examples, if a bank could help resolve the financial challenges identified above (see p11), would it automatically become the bank of choice of millions of carers? If a taxi firm recognised that some of its customers were carers and trained its workforce accordingly, would it win new business and distinguish itself from competitors?

further into adulthood, they are also increasingly likely to have their own families, and may have to balance caring responsibilities for children alongside caring for their parents and engaging with employment or education.

Cultural factors also play a role in who takes on caring responsibilities, based both on community expectations and on the structural disadvantages faced by particular cultural groups. One participant highlighted the vast class disparities in South Africa in relation to access to formal services. Services in more disadvantaged areas are often under-resourced or non-existent, and so there is a reliance on an extended family network to meet the needs of a person living with dementia. While families may wish to take on this role, it is important to unpick the extent to which this is based on necessity alongside unchallenged cultural assumptions.

The concept of a carer, and the extent to which family carers identified themselves in this way, was seen to vary among different groups, particularly in relation to culture and age. Defining oneself as a carer was seen as a key requirement for accessing support,



and yet many older people see their role as simply a continuation of a spousal relationship. Similarly, there is a further barrier to self-identification for people whose cultures do not recognise the concept of a carer. As one participant noted:

*"Every family brings its own individual and family history, but they also exist within their ethnic and national culture, which influences how they deal with the caregiver role."*  
(Carers organisation, US)

An example of this was discussed in relation to Latino culture, in which daughters are typically raised to take care of their parents in older adulthood as part of a 'natural' sense of duty. It is important to recognise that, despite differences in how people may perceive themselves, they will still experience the same challenges as other carers. However, the barriers they face in talking about these difficulties may differ, and efforts are needed to normalise this kind of conversation and enable carers to share their experiences with others.

### Reflection (for society)

How do our social and cultural expectations inform how we view these issues?

As an example, imagine a 'typical' carer of someone with dementia, and picture them in terms of gender, age, ethnicity and social background. To what extent are these assumptions built into how we view carers and the support we then provide?

**Principles of effective support:** participants highlighted a range of support needs which are experienced by carers, and discussed the extent to which current service provision is able to meet these needs. It was clear from these discussions that there is not a simple solution which can address such a complex range of experiences. However, there were a number of principles which could be drawn out from participants' responses:

- *Diversity of support services:* a key theme that emerged from the interviews was the need to recognise the diversity of carers and to respond to them as individuals with complex and varied needs. In practice, this means multi-method interventions which may include elements of psychoeducational approaches, peer support and information provision in a variety of formats. There is a clear need for flexible services that are able to fit with the needs and values of the carer and the person they are supporting. This could include culturally-specific provision; services that can be accessed when they are most needed, including outside regular office hours; and short breaks which enable carers to maintain their employment.

- *'Re-imagining respite':* while participants recognised the value of 'respite' for many carers, there were concerns about the limited ways in which it was viewed and the very negative overtones of the phrase 'respite'. Participants suggested that a more creative approach might begin from the interests of the person with dementia and their carer. The standard approach is often for the person being cared for to have a short stay in a residential unit, thereby enabling the carer to take a break. However, for many carers this increases anxieties if the person being cared for does not enjoy the short break, isn't well cared for, or comes back in a state of agitation or distress. Instead, it may be possible for a couple to go away or to take part in a shared interest together, but with additional support so that they do not have to be 'carer' and 'caree' during the activity but can instead reconnect with their relationship.

- *Promoting carer choice:* according to one participant, the question that is most commonly asked of carers is 'What do you need to carry out this care better, or for longer?' The question that is not asked is 'What do you need to have a life?' Similarly, the focus on maintaining the carer in their caring role may be appropriate for some, but can lead others to feel that they have no choice but to continue, even if it is increasingly difficult for them. For both spousal carers and adult children, non-judgmental support is needed to help people reflect on their options and consider what is safe and manageable for them and the person they are caring for, regardless of any guilt they may feel.

- *Carer inclusion*: the need for the inclusion of carers in policy, practice developments and research emerged as a clear theme in the interviews. One driver for this was the acknowledgement of carers' expertise based on their experiences: where there has previously been a lack of carer involvement, this has led to the development of systems which are not logistically or financially viable, and not needed or wanted by carers. Carer advocacy organisations have played a key role in bringing the carer perspective to service development processes, research agendas and policymaking forums, but involvement is far from universal and there is scope for greater inclusion, particularly in countries with less developed frameworks for supporting carers.

### Reflection (for health and social care)

How can we move from 'what do you need to carry on caring (or to do more)' to 'what do you need to have a life?'

Can our services respond to the diverse needs of carers and people with dementia (or is there a 'one size fits all' approach)?

How can we meaningfully 're-imagine respite' (and ban the term 'respite' altogether)?

Are carers involved in contributing their experiences and expertise to the design of services?

### 3. Good Practice Examples

During the course of our interviews, participants identified a number of examples of what they saw as good practice in policy and service delivery which supported carers in their roles. Some of these projects were specifically designed to meet the needs of carers, while others were aimed at people with dementia but had additional benefits for carers. These include:

**Medicalert Wanderer Safety Programme (US):** created in 1990 and operated by CaringKind in partnership with Medicalert and the New York Police Department (NYPD), this multi-agency programme identifies and supports people at risk of 'wandering' and their carers. It uses a low-tech bracelet with

a personalised medical ID, which connects with a personal emergency health record with details such as medication, allergies and next of kin. There is a 24/7 emergency response number which carers can call, and there is a detective assigned to the project from the NYPD missing persons team. The programme has a high success rate and provides reassurance to carers, as well as feeling like a concrete step they can take in response to concerns about 'wandering.'

**Connect2Culture programme (US):** this programme was developed by CaringKind and provides training for museums, art galleries, theatres and other arts centres in New York so that people with dementia and their family member can participate in cultural life.

**Culturally-specific support groups (US):** CaringKind operate a range of support groups that aim to meet the specific needs of particular groups of carers in New York. Most of their programmes are run in English, Spanish, Cantonese and Mandarin, and they run specialist groups relating to particular forms of dementia and different contexts of care (such as long-distance carers) in recognition of the diversity of experience among carers. The groups provide a way of acknowledging the uncomfortable feelings people may have and may find difficult to express, and can help carers to process and normalise these feelings.

**Dementia Co-ordinators (Norway):** at point of diagnosis, people with dementia are allocated a Dementia Co-ordinator, a specific contact person who will remain with them through the course of their illness, and whose role is to support both the person with dementia and their carer and help them access their rights. This is a trained healthcare professional such as a nurse or occupational therapist with specialist knowledge in gerontology or dementia.

**Carer School (Norway):** Carer School aims to equip new carers with the knowledge and skills they may need for their caring role. It is run for three hours a week over a six-week period and has been received positively by carers in Norway. Carers have found it particularly beneficial to learn about the law and their rights as carers, to understand the symptoms of dementia and how it progresses, and to hear from and talk to other carers.

**Dementia Friends (UK):** the Alzheimer's Society now has one million volunteers on its Dementia Friends and Dementia-Friendly Communities schemes, which have the potential to bring about a culture change so that dementia is seen as all our responsibility, and not just a matter for care services.

**10.60.06 programme (UK):** the 10.60.06 programme builds on principles from Barchester Healthcare's 'Memory Lane Community' approach. It is a training and accreditation programme designed to enhance both the dementia care environment in participating homes and to improve interactions between staff, people living with dementia, relatives and health professionals. It focuses on reducing distress, increasing well-being and improving quality of life.

**Young Dementia Group (Berkshire, UK):** this is an activity group aimed at supporting people with dementia and their carers. Activities include a walking group, where carers and the people they are supporting set out together and then divide into separate groups, each with facilitators, before coming back together at the end. The activities are led by the preferences of those taking part, and have also included rock climbing and kayaking. Outcomes have included lower rates of prescribing anti-psychotic medication and of admissions to care.

**Peer mentoring programme (Norway):** run by the Norwegian Health Association (NHA), this project has recruited over 80 carer volunteers who have received training and support to be able to support other carers. Confidentiality is protected, and carers can contact peer mentors by phone, email or face-to-face. The organisational support from NHA also gives the mentors a sense of safety.

**iCARE (US):** iCARE is a small grassroots group set up to train family caregivers to be advocates on behalf of themselves, the people they are caring for, and within the political system.

**Music and Memory (US):** created by Dan Cohen, this project creates individualised playlists for people with dementia made up of music from their youth, and can have a transformative impact on their well-being. It has previously been used in nursing homes, and there is currently a pilot project taking it into the community. It has so far been funded by some local health departments in the US. In Canada, funding has been gained so that everyone who could benefit from the programme can access it.

**Dementia-friendly spaces (Norway):** as part of a project initiated by the World Health Organization (WHO) on Age and Dementia-Friendly Cities, Boots conducted a pilot project in an Oslo pharmacy branch. This included training staff in how to communicate effectively with people with dementia and their carers, including through the use of tone of voice, body language and allowing time for people to process the information given. There were also a number of initiatives that were put in place in store with the aim of making the experience more welcoming for older people and those with dementia. This included placing an increased number of chairs in retail areas so people could sit down while waiting, increased visibility of the ticket machines so people could get a ticket for their place in the line, and providing small magnifying glasses by shelves and at till points. Branch staff were enthusiastic about the project, and as a result of the positive results it achieved, the training was later rolled out across the city to grocery stores, taxi companies and other businesses. Examples of other measures in the project were putting more benches across the city to encourage physical activity, and a joint project run by the city council and bus service to put in place a bus-taxi service, which people can book like a taxi to pick them up from their home to take them to the shops or the doctor (only needing to pay the bus fare).

### Reflection (for society)

These good practice examples are inspiring, but none of them are rocket science. If we want something like this in our local community, how could we go about making this happen?

# CONCLUSIONS AND RECOMMENDATIONS

This policy paper has reviewed the experiences and needs of the carers of people with dementia in a number of different national contexts around the world – via published research and the policy, practice and personal experience of key stakeholders (including people with experience of being a carer and those involved in carer-led organisations or initiatives). While potential responses may vary significantly according to different cultural, social, economic, and political contexts, a number of the underlying themes seem remarkably consistent, including:

- The importance of emotional and social needs, alongside more tangible health and financial needs
- The need to recognise the diversity of carers and caring contexts, so that responses are tailored to individual needs and circumstances
- The need to provide much more and much better support, without assuming that carers continuing in their caring role is necessarily a good outcome
- The need to tackle stigma and social isolation, and to challenge cultural assumptions about the nature of care
- The overriding importance of relationships – between the carer and the person being cared for, between members of local communities, and between the family and formal services

In addition to urging policy makers and service providers to respond to these themes when designing future support, our participants also proposed a small number of additional recommendations which they wanted to flag to governments, funders, health and social services, campaigners and general members of the public:

**1. New research to understand frailty:** as the population ages, there are growing numbers of people with multiple conditions and increasingly complex needs. This is challenging traditional models of single disease, which have proved unable to accurately describe the difference between older adults who age successfully, and those who develop multiple medical conditions and the adverse consequences of these. Alongside research into specific conditions (such as dementia), what is also needed is a focus on frailty (a clinical syndrome that affects people as they age, and is associated with outcomes such as falls, immobility and mortality). Frailty can include weakness, weight

loss, cognitive impairment and a vulnerability to poor health and social outcomes, and it is important we learn more about how people age, which factors contribute to successful ageing and which factors lead to frailty.

To do this, we could recruit a cohort of people and to follow them through over time. Traditional cohort studies tend to rely on high numbers of people and focus on data which is simple to collect. However, what might be needed going forwards is a much more detailed study which recruits a smaller number of older people but which includes detailed ‘phenotyping’ (that is, collecting much more detailed clinical, biological, social and psychological data in order to understand the causes, trajectories and tipping points of frailty).

Through developing such a uniquely characterised longitudinal cohort of older people, researchers could seek to:

- Identify those most at risk of frailty (with dementia one of the conditions which people might develop)
- Target the drivers of frailty to develop new approaches to delay progression or even reverse frailty altogether

**2. Helping people to understand that they are ‘carers’ and signposting them to support:** although the health and social care system labels people providing support to family, friends and neighbours as ‘carers’, this isn’t a term that many people understand. Often, people see themselves as a husband/wife, a son/daughter, a friend or a neighbour – not as a ‘carer’. This might be particularly the case with older couples, who may be seen by formal services as a ‘service user’ and a ‘carer’ – but who, in reality, are simply a couple looking after each other. This then means that many ‘carers’ don’t get access to the services that are there to support them (in countries where such support exists). According to research by Carers UK (2016, p.3), for example:



*“Based on findings from Carers UK’s State of Caring Survey 2016, examining the experiences of over 5,682 current carers – this research explores the time it takes for people to recognise they have taken on a caring role, and whether they had missed out on support because they simply didn’t think of themselves as a carer. The research also looks at the impact that missing out on support can have across carers’ lives.*

*The findings are stark. They demonstrate that the majority of carers take years to recognise their role, missing out on crucial financial, practical and emotional support in the meantime. This research demonstrates that, by not receiving support at an early stage, the negative impacts of caring are intensified with many carers missing out on benefits and entitlements and others forced to give up work altogether. On a personal level, a lack of practical help can have a huge impact on health and well-being, from long-term physical health effects such as back pain, to mental ill health and social isolation and as a result of caring without a supportive network.*

*The longer it takes to identify as a carer the more likely it is that carers will struggle without the support and advice they need. Frontline professionals, such as GPs, social workers and pharmacists play a central role in ensuring carers are identified and then guided to support as early as possible in their caring journey.”*

In the passage above, Carers UK cite the role of GPs, social workers and pharmacists, and there is a clear link here to the work that the Walgreens Boots Alliance has been doing to train its pharmacists to identify and support carers (see ‘good practice examples’ above). However, our interviews suggest that we need to do more outside of formal ‘care’ settings to make sure that carers are identified and supported. In the case of the Walgreens Boots project, for example, there may be scope to partner with a voluntary organisation (such as the Carers Trust in a UK context), so that pharmacists can signpost people to local carers’ support groups and services (perhaps with relevant information and advice staff co-located on site). This could be evaluated to understand the impact on the health and well-being of carers over time, but it may also have positive knock-on effects for Boots staff – many of whom will be carers themselves and may also benefit directly from access to such information and advice without the stigma of

having to approach formal services. In the process, there may also be scope to do specific work around the needs of young carers, older carers and/or carers from black and minority ethnic communities, since some of these people may be particularly unlikely to self-identify as carers without this brokerage/screening role. Given the international scope of the Walgreens Boots Alliance, moreover, there may be scope to run and evaluate such projects in both the UK and the US (as but two examples), thus shedding light on (but still demonstrating what is possible) in very different policy contexts.

Other examples of this underlying theme include the role of banks in taking more proactive steps to respond to issues raised above about financial needs, or the role of the police, taxi firms, museums or technology companies in some of the ‘good practice examples’ cited above.

**3. Building advice and information into everyday life:** given that information and advice is patchy in its availability, and tends to be provided too late in the process, a number of participants proposed ways in which we could try to build access to information into everyday life so that people and families had greater scope to plan ahead. In the UK and in Norway, new families receive a ‘baby box’ containing products for the baby and parenting information (sponsored by companies whose products are contained in the box). Mirroring this, there may be scope for what participants described as “a care package” – a collection of information about the impacts of ageing (including early signs of dementia), financial planning for later life and available health and social services, which could be distributed to everyone at a particular age. As with baby boxes, there may be scope for this to be funded commercially, but with formal services vetting and agreeing the information provided.

Above all, the main messages from this research are that dementia is a growing issue around the world which we ignore at our peril, and that the numbers of families affected mean that responses need to cut across the whole of society and be incorporated into every aspect of community life – this cannot be the responsibility of health and social care services (or of families) alone.

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*NB - This reference list only includes sources cited in the main body of the policy paper. For full details of our literature review and all studies included/key findings, see the separate PDF summary published via the news item on the School of Social Policy website alongside this paper.*









## APPENDIX A: METHODS

*Literature search:* We searched the following databases for material on the needs of the carers of people with dementia: HMIC; Medline; Embase; Cinahl; ASSIA; Social Science Citation Index; Social Care Online; and Scopus. Searches were international in scope (albeit confined to English language material), combining terms around:

- **‘Carer’** (Carers; Young carers; Caregivers; Carer support; Caregiver burden; Informal carers; Family carer)
- **‘Dementia’** (Dementia; Pre senile dementia; Senile dementia)
- **‘Needs’** (Assessment; Needs assessment; Social support; Support groups; Support schemes; Support networks; Health services needs and demand; Humans; Wellbeing)
- **‘Experiences’** (Experience; Views; Narratives; Qualitative research)

Material was included if it reported original research findings on the needs and experiences of carers of people with dementia. Excluded were:

- Studies of transition to/living in residential care, respite care and end-of-life care
- Research focusing primarily on the needs of service users (with carers mentioned but not the main/a significant focus)
- Studies published prior to 1999 (the date of the first national carers strategy in the UK)
- Good practice guidance that did not report original research (although this was noted for background information)

Included material was read to draw out: insights into the experience and needs of the carers of people with dementia; the support available; good practice examples; and recommendations for future policy and practice.

*Stakeholder interviews:* drawing on existing national and international networks, we conducted interviews with 15 key stakeholders from the UK, North America, Australia, Norway and South Africa. Their expertise spanned a range of disciplines and specialisms, including carer support, carer-led organisations, advocacy, major employers seeking to support carers, policy, social work, medicine and research. Participants took part on the basis that they would not be named individually and that data would be used in a non-attributable manner. They were asked:

- What are the needs of carers of people with dementia?
- What sources of support exist to help carers?
- How well do these meet people's needs?
- Are there any unmet needs?
- Are there good practice examples of policies, services, projects and/or organisations that you know about?

This aspect of the research received research ethics approval from the University of Birmingham Humanities & Social Sciences Ethical Review Committee.



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