

# Dementia

## Equity and Rights





# Contributors

Many people contributed to this report, either by supplying a case study, a photograph, or proof reading the document. We are grateful for their help, for without their contribution this unique piece of work would not be complete.

The individual chapters were written by the following voluntary and community sector organisations. All the organisations, with exception of Joseph Rowntree Foundation and Young Dementia UK, are members of the Strategic Partners Programme which brings together expertise from the voluntary and community sector. The Programme has 22 programme members, six of which are consortia. Partners work together on key aspects of health, social care, and public health policy with system organisations - Department of Health (DH), Public Health England (PHE) and NHS England (NHSE) - on behalf of patients, service users and the wider public. The strategic partners work directly with policy makers and co-produce specific projects. This publication is an example of that co-production.

## **Age UK**

Age UK help people enjoy a better later life by providing life-enhancing services and vital support. They develop services and products that are specifically designed for people in later life, and fund pioneering research into aspects of getting older. They offer information and advice to help and support people in later life, developing services and products that are specifically designed for older people, and funding pioneering research into age-related conditions.

## **Joseph Rowntree Foundation**

The Joseph Rowntree Foundation is an independent organisation working to inspire social change through research, policy and practice. They work in partnership with private, public and voluntary sectors, as well as with individuals and communities. Using evidence and experience, they search for the underlying causes of social problems and demonstrate practical solutions in order to influence lasting change.

## **Mental Health Providers Forum**

MHPF is the national alliance of voluntary sector mental health providers, facilitating collaborative and cooperative partnerships across the sector to improve mental health in England.

Representing its membership, MHPF is focused on supporting the delivery of services which make a positive and demonstrable difference to people with mental health needs. It is an organisation which promotes innovation and works to shape and influence the growth of the voluntary and community sector, improve outcomes for individuals and evidence best practice to improve service delivery across health and social care.

## **National Care Forum, Voluntary Organisations Disability Group**

The National Care Forum (NCF) and Voluntary Organisations Disability Group (VODG) are representative bodies for social care providers and pan disability organisations with an exclusive focus on not-for-profit provision. They provide a unified focus on voluntary sector disability and care, representing over 180 organisations. They share a strong focus on quality improvement and with over 170 members who are employing over 180,000 staff, they have considerable reach into, and across, the disability, health and social care sectors. Their pan-disability approach encapsulates many of the population groups prioritised in the Strategic Partners programme, including a strong focus on addressing inequalities.

# Contributors

## **Race Equality Foundation**

The Race Equality Foundation promotes race equality in social support (what families and friends do for each other) and public services (what 'workers' do with people who need support). They do this by exploring what is known about discrimination and disadvantage; developing evidenced-based better practice to promote equality; and disseminating better practice through educational activities, conferences, written materials and websites.

The Foundation works with a range of national and local partners from the community, voluntary, statutory and social enterprise sectors who are delivering health, housing, social care and parenting support.

## **The National LGB&T Partnership**

The National LGB&T Partnership is an innovative and inclusive England-wide group of LGB&T voluntary and community organisations using a wealth of talent and experience, who are committed to reducing health inequalities and challenging homophobia and transphobia within public services. The Partnership members have joined forces to influence the policy, practice and actions of government and statutory bodies, in particular the Department of Health, for the benefit of all LGB&T people and communities across England. The Partnership will ensure that health inequalities experienced by LGB&T people are kept high on the Government's agenda and that best use is made of the experience and expertise found within the LGB&T voluntary and community sector. The Partnership works to ensure the sustainability of the LGB&T sector and enable it to engage with Government and statutory bodies, such as the Department of Health, at a strategic level to improve service delivery.

## **Women's Health and Equality Consortium**

The Women's Health and Equality Consortium (WHEC) is a partnership of women's charity organisations, all of whom share common goals of health and equality for girls and women. By pooling their expertise, information and resources as WHEC, they can speak with one voice and more strongly influence decision-makers and government, making sure policy reflects the real needs of girls and women. They are an agency that works to improve the sustainability of the women and girls health and social care sector and strengthen their capacity to engage with the health and social care systems. Through this, they are committed to reducing women and girls' health inequalities by building the capacity of their own women's organisations and thereby strengthening the voice of women at a national and local level.

The Women's Health and Equality Consortium (WHEC) consists of: Women's Resource Centre (WRC), FORWARD UK, Imkaan, Maternity Action, Positively UK and Rape Crisis (England and Wales).

## **Young Dementia UK**

Young Dementia UK is a charity that supports young people whose lives are affected by young onset dementia. They do this by developing specialised, person-centred, enabling services for individuals with young onset dementia and their families; providing high quality services from diagnosis to beyond bereavement; helping people understand the impact of young onset dementia; and by working collaboratively with individuals, families and organisations to improve the experience of living with young onset dementia.

# Foreword

Equity and rights are terms which historically have not been closely associated with dementia. That is one reason why this publication is so important. Dementia is an umbrella term for a range of different conditions, all of which physically affect the brain, so it is often referred to as an organic brain disease. As a result of this, research, policy and practice has tended to focus on trying to find effective treatments and interventions for people with dementia. But it is only fairly recently that any significant attention has been paid to dementia, equity and rights. As with other issues affecting older people, (although dementia does occur among some younger people as this publication makes clear) it has largely been ignored until demographic and economic pressures have become too great. In some respects, dementia is playing catch up with other population groups affected by different health conditions and disabilities where issues of equity and rights have been central to discussions for a longer period of time.

Age and disability are just two of the 'protected characteristics' that this publication covers in respect of dementia. Dementia has, until recently, not been described in disability terms, but it is clear that the various impairments that the condition gives rise to mean that people with dementia have protection under the law as people with disabilities. Awareness of this is growing, partly because more people with dementia are describing it in these terms through networks like the Dementia Engagement & Empowerment Project (DEEP), and through publications such as *Dementia, rights and the social model of disability*.<sup>1</sup>

But this publication is important because it looks across all the other protected characteristics as well – gender, ethnicity, sexual orientation, gender reassignment, and socio-economic status. It flags up issues where the risk and prevalence of dementia may vary for different groups and how access and provision of services must take into account the needs of particular groups. Minority groups often feel left out or misunderstood within systems created for the generic population. And for a condition that is likely to be life changing, potentially distressing for individuals and their families and friends, and still lacking universally effective treatments, it is essential that people, who may have been ignored, excluded or discriminated against for other reasons do not experience further inequalities because of having dementia.

Recognising that people from minority groups share intersecting protected characteristics informs the debate around this work and engagement with other organisations ensures that every minority group and protected characteristic is represented.

People with dementia are citizens of our society with rights - this publication provides invaluable information about those rights and should help to promote greater inclusion, access, equity, participation and empowerment for different individuals and groups affected by dementia. Marginalised groups have often had to be robust, resourceful and problem solving and therefore have insights and learning to share that addresses inequality and promotes best practice for all.

*Toby Williamson, Royal Surgical Aid Society and Mental Health Foundation*  
*Rowena McCarthy, Service User*

<sup>1</sup> Mental Health Foundation (2015) *Dementia, Rights and the Social Model of Disability* [www.mentalhealth.org.uk/publications/dementia-rights-and-social-model-disability](http://www.mentalhealth.org.uk/publications/dementia-rights-and-social-model-disability)

# Executive summary

The prevalence of dementia in the UK is estimated to reach over 1 million by 2025.<sup>2</sup> Anyone, regardless of gender, sexuality, race, ability, or socio-economic background can develop dementia; however some groups have higher prevalence rates and experience greater disparities in the care they receive and the support that is provided to carers.

This publication seeks to highlight the main issues arising for people with dementia and carers from the following population groups: the oldest old, young onset, people with disabilities, black and minority ethnic people (BME), women, lesbian, gay, bisexual and transgender people (LGB&T), and different socio-economic populations. It considers the prevalence of dementia within each group and the needs and experiences of people living with dementia and carers within each protected characteristic group. It also provides information, recommendations and resources for commissioners, service providers, service users and their carers to ensure that the best possible care and support to people living with dementia and their carers is expected and delivered.

In addition to highlighting the issues for individual groups, this publication asks readers to consider dementia as a disability and to take a social/rights based approach to the way we respond to dementia. Using the social model of disability takes a person-centred view of disability that additionally tries to ensure the environment does not further disadvantage people with dementia. It also raises issues of the rights of people with dementia under the law, and considers how dementia is experienced and perceived by people with dementia and their carers. Additionally, a rights based approach raises issues around how dementia is viewed and discussed in public. *“In this social model people with dementia are centre stage, with their voices elevated, and are recognised as equal citizens with rights. They are the agents of change and their agency is valued and recognised.”*<sup>3</sup>

This publication is not exhaustive and readers will need to consider the issues of other groups where information may be limited. For example, the experiences of homeless people and offenders living with dementia is an emerging issue and an area that requires further research. Both groups experience considerable health inequalities and will have unique health and care needs and experiences that need to be addressed.

Presented below are some overarching themes that service users and their carers might find helpful and can underpin commissioners and service providers’ approach to equity issues in dementia:



# Overarching themes

## **1 Seek to understand each person with dementia, and carer, as an individual**

The analysis in this document demonstrates how much an individual's experiences of dementia can be shaped by their personal circumstances. This suggests that significant value can be added by commissioning and providing services that seek to understand each individual's personal context and aspirations. This may include life story work and similar approaches.

## **2 Consider different pathways to diagnosis**

Many of the characteristics in this document are associated with later diagnosis and therefore poor outcomes such as emergency admissions that can follow. Consideration should be given to whether efforts to improve diagnosis rates can be enhanced by reaching out to more marginalised communities and individuals, such as some BME communities, people with learning disabilities and older LGB&T individuals, and offering tailored entry routes to diagnostic pathways that are less likely to be off-putting.

## **3 Explore tailored support options following diagnosis**

Some mainstream activities and support for people with dementia can feel alienating to people with disabilities such as sensory or mobility impairments, or who are less able to engage with domestic cultural norms. Lack of engagement with support can contribute to poorer outcomes and experiences.

## **4 Enable a variety of peer-support options for people with dementia and carers**

Dementia can be isolating, and particularly so for individuals such as younger people with dementia (who may feel isolated from a largely older peer network) or from BME communities (who may not find mainstream services culturally appropriate). Isolation can reduce an individual and carer's ability to self-manage. Supported peer networks can begin to address these issues, allowing people to learn from people who have similar experiences, reducing their likelihood of poor outcomes.

## **5 Tailor engagement with families and carers**

Carers are fundamental to an individual's experience of dementia. They will have specific needs as well, including language, culture, and their possible role as carers for a pre-existing disability. Both the individual with dementia and their carers will benefit if these differences are recognised, and support being provided that enables carers to fulfil their roles with appropriate information and support.

## **6 Work through community intermediaries**

As with many other services, community intermediaries such as local community groups are vital to understanding local needs, and are pivotal partners in developing appropriate responses. They can help facilitate access and delivery of messages to groups that may distrust formal services (e.g. some BME communities), or to help commissioners understand the needs of particular groups with dementia (e.g. LGB&T individuals in a given locality).

## **7 Locally tailored public-awareness campaigns**

Consideration should be given to raising public awareness of the variety of types of dementia, and dispelling myths (e.g. that younger people do not get dementia, that nothing can be done to support people to live well with dementia). Different communities have different misconceptions about dementia that require specific messages to address them. To get the maximum benefit from local information

# Overarching themes

campaigns, efforts should be taken to understand the local misconceptions and other information needs, and develop targeted messages.

## **8 Professional understanding of equity issues and how this affects individuals**

Professionals should be supported to understand some of the issues affecting specific groups. For instance, dementia is very common in people with Down's syndrome but they do not always present with traditional memory loss and their learning disability often overshadows the early symptoms. Professional understanding of this possibility may help mitigate late diagnosis and lack of appropriate support.

## **9 Exploit local data resources**

It is possible to develop a local profile of many protected characteristics related to dementia using common data sources and techniques. This can enable commissioners to prioritise their action.

## **10 Embed in research and evaluation**

Local and national research needs to take account of the wider variety of characteristics that can affect people's experience of dementia. Dementia-related studies should consider building in equity from the start, and consideration should be given to commissioning dedicated studies to develop our understanding of particular characteristics.

<sup>2</sup> Alzheimer's Society (2014) *Dementia UK: Second edition* [www.alzheimers.org.uk/dementiauk](http://www.alzheimers.org.uk/dementiauk)

<sup>3</sup> Mental Health Foundation (2015) *Dementia, Rights, and the Social Model of Disability: A new direction for policy and practice?*, August 2015.



# Introduction

This document has been developed by a group of individuals from voluntary sector organisations who are passionate about ensuring that people with dementia from protected characteristics are able to access appropriate support.

The aim of this publication is to collate disparate sources of information and analysis into a single document that can help interested people understand the breadth of the issues, show them where to find more information, and give case study examples from which they can learn.

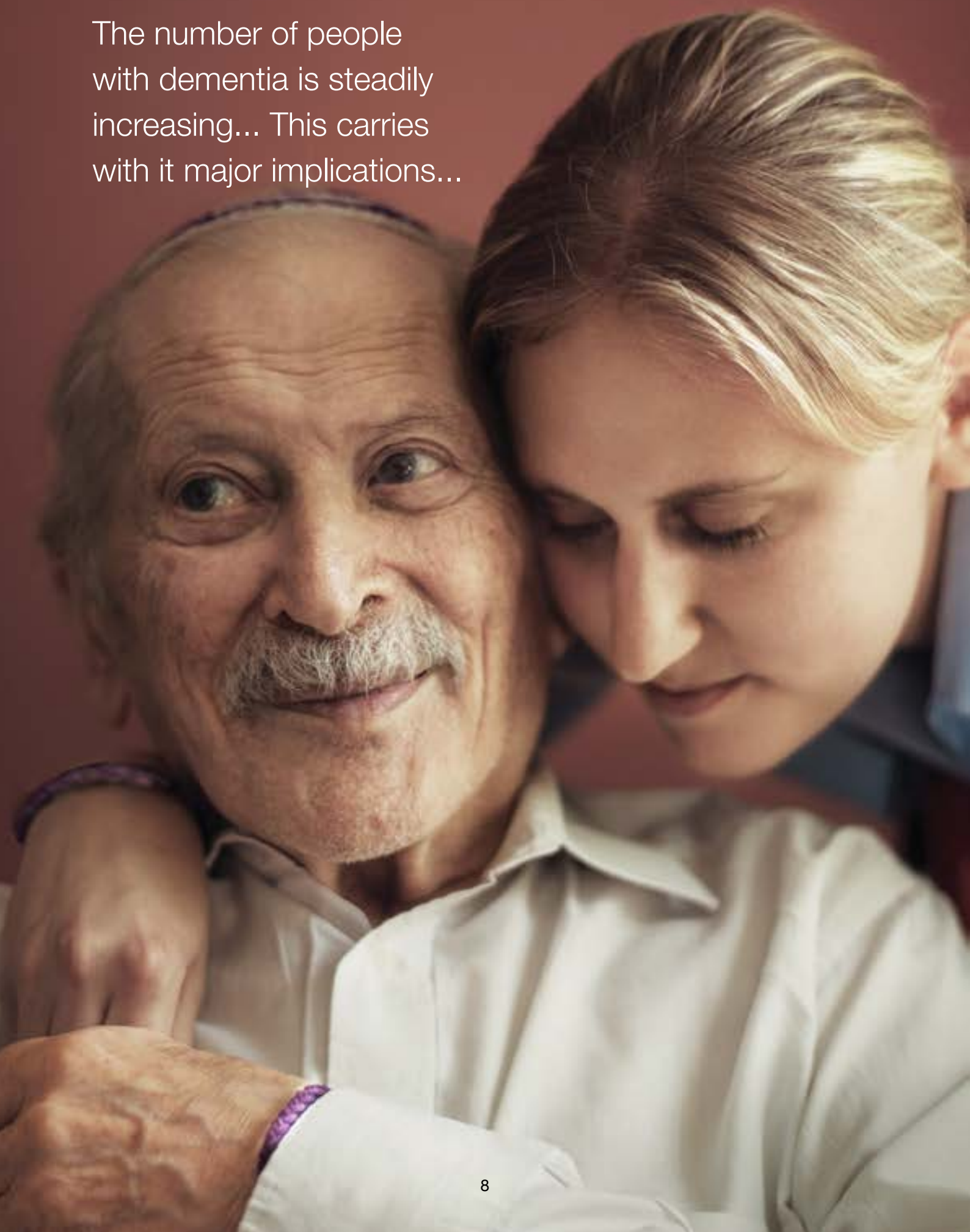
To our knowledge this is the first attempt to bring together analysis of this kind, and it draws on a wealth of knowledge from specialists with backgrounds in dementia, equalities, policy, and data analysis.

There are separate sections on each equity characteristic that highlight the specific issues facing each group. Included in each section is a case study that illustrates the particular challenges individuals face in accessing appropriate diagnosis and support and the difference it can make to living well with dementia when appropriate diagnosis and support is available. The amount of information in each section (recognising that all characteristics are not represented) varies considerably and reflects the variation in availability of information for each characteristic. It is hoped that this publication will stimulate interest and encourage more research into the particular issues faced by people from protected characteristics with dementia.

Finally it is worth remembering at the outset that just because an individual has a characteristic this does not mean that characteristic alone defines their experience of dementia. Many individuals will share multiple characteristics covered by this document, as well as bringing their whole life experience and personal context with them.



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# Oldest people with dementia

Lead contributors: Emma Bingham and Rebecca Stanley, Age UK

## Introduction

People over the age of 85 are now the fastest growing demographic group in the UK. The Office for National Statistics (ONS) estimates there are currently 1.5 million people in the UK over the age of 85; by 2050 this will have grown to 5 million.<sup>4</sup> This group is often referred to as ‘the oldest old’.

The number of people with dementia is steadily increasing with a substantial proportion of oldest old affected by this condition. This carries with it major implications for the individual as well as society. A better understanding of dementia in this population is thus of increasing national and global importance.

This cohort not only has increasing rates of dementia but also complex needs compounded by a range of co-morbidities.<sup>5</sup> Increases in complex health conditions will put significant pressure on services that are already under pressure to provide care and support to the oldest old.<sup>6</sup>

Increased demand for support services will be driven both by the increases in the numbers affected and the shift in the age distribution towards a majority of the oldest people, who tend to be frailer and to have more limited informal support networks.<sup>7</sup>

The oldest old are often physically, cognitively or socially frail (i.e. need help with basic activities of daily living or have a diagnosis of dementia, delirium or both or have poor social support networks).<sup>8</sup>

If admitted to inpatient hospital care, the oldest old have the highest readmission rates and highest rate of long term care use after discharge.<sup>9</sup> Declining health in the oldest old poses a threat to people’s identity, particularly when dementia is involved. Uncertainty and a sense of precariousness resonate in the lives of the individual and their families.<sup>10</sup> Research has shown that loneliness can speed up cognitive decline and memory problems. To prevent decline of dementia, it is important for older people to maintain friendships and strong family connections.<sup>11</sup>

## Effect on prevalence of dementia

*Prevalence of dementia nearly doubles with every five year increase in age.* More than 50% of centenarians may be expected to suffer from dementia.<sup>12</sup> Research has shown that rates can be expected to be 0.8% in the group age 65–69 years and increase to a much larger rate of 28.5% at age 90 years and older.<sup>13</sup>

## Impact on needs of people with dementia and carers

*Carers aged 85 and over are more likely to provide 50+ hours of care a week compared with other older carers.*<sup>14</sup> Given the complex conditions that inevitably will be involved for the carer and their loved one, an increasing amount of support is required from a number of wrap around services to ensure a good quality of life for both.

People can live well with dementia and their carers can be supported; however there needs to be joint working across governments, the health service, social care, the voluntary and independent sectors and the wider community.<sup>15</sup>

## Actions commissioners and providers can take, and questions they can ask of their current approach, to drive improvement

- ▶ **Take a holistic approach** – This approach takes into consideration other health conditions as well as social support needs. A holistic approach puts older people in control of their own health and wellbeing, enabling them to regain and sustain their independence and improve their quality of life and coordinating care through an effective, multi-disciplinary team.





- ▶ *Care management assessments* – Should be considered to ensure correct care and medications are adhered to out of hospital, and that there are no challenging behaviour problems or adverse reactions to prescriptions. This is important for the oldest old whose carers will often be part of the oldest old also and may have their own complex conditions to consider.
- ▶ *Care homes appropriately equipped* – Care homes need to be equipped to take care of the oldest old with dementia who often come with a more complex set of conditions and a larger set of needs than others.
- ▶ *Social prescribing* – An important method that can often have numerous health benefits both medically (weight loss, decreased blood pressure etc.) and more holistically by decreasing isolation and increasing social connectedness.
- ▶ *Support for patients with co-morbidities* – Hospitals need to have methods in place to be able to support the oldest old who are frequent users with co-morbidities. This will ensure they can get the care required to attend to the reasons for increased use of hospital and emergency services.
- ▶ *Further research on oldest old* – Despite the fact that the oldest old represent the largest and fastest growing population with dementia, the majority of dementia research focuses on the younger old. An improved understanding of dementia in this oldest population is therefore of great importance.<sup>16</sup>
- ▶ *Work with voluntary sector partners* – Age UK are currently working with an integrated care model which demonstrates the benefits of involving the voluntary sector, both in terms of reducing the demand on health services and improving well-being of individuals.<sup>17</sup>

## Case study Age UK

Mr A is a gentleman who is in his 80's. He lives with his wife Mrs A in the North East of England and has a family member, Miss B, who lives nearby. Mr A was diagnosed with Vascular Dementia 12 months ago and prior to that had been a very active gentleman who enjoyed spending time with his family and, as his family describes, "pottering around the house".

Mr A was referred to his local Age UK service after one of the hospital social workers had spent time with him and his family and assessed that there was more support needed. The social worker advised that she had assessed a family member (Miss B) as suffering from carer stress.

An Age UK team member met separately with Miss B who shared the family's experiences over the previous 12 months since diagnosis. Miss B advised that she had concerns regarding Mr A as his memory, mood and mobility had been declining gradually since the diagnosis. Miss B also told how she also had concerns regarding Mrs A as she had shown signs of issues with her memory. During the conversation Miss B became tearful and was demonstrating signs of stress, guilt and upset at the change of her role within the family. The Age UK worker reassured Miss B and provided a safe place to share her feelings. At the conclusion of the session Miss B disclosed that it had been the first time she had shared those feelings with someone else.

Mr A was eventually discharged home but was readmitted within 2 days due to a fall at home. It was later identified he was also experiencing a

social crisis. On admission, it was discussed that his home was no longer suitable and Miss B would need to begin looking for a residential home.

Age UK worked with Miss B for a number of weeks on stress management, ways in which to deal with certain situations and to help her regain her confidence and coping mechanisms. Throughout the process Miss B was offered information in regard to quality reassurance measures so she was able to investigate reports on the individual facilities and also information on finance threshold. When Miss B began to look at residential homes for Mr A, an Age UK team member accompanied her to a second viewing to offer support.

Once the matter had been resolved, Miss B advised that due to the work Age UK had been able to offer in regards to stress management and rebuilding her confidence, she was able to cope with the big changes occurring.

*"I don't know what I would have done without Age UK. To have someone there for advice and support but also a shoulder to cry on was invaluable"*

Further information on Age UK dementia pilot sites can be found here:

[www.ageuk.org.uk/professional-resources-home/services-and-practice/dementia-pilot-programmes/overview](http://www.ageuk.org.uk/professional-resources-home/services-and-practice/dementia-pilot-programmes/overview)

For your local Age UK listings, please visit your local Age UK office or website.

# Oldest people with dementia

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# Young onset dementia

Lead contributor: Tessa Gutteridge, Young Dementia UK

## Introduction

‘Young onset’/‘early’/‘working age’ dementia is defined as dementia occurring when under 65 years of age. The most recent estimates suggest there are more people with young onset dementia (YOD) in the UK than previously thought. It is now estimated that there are over 40,000 people aged under 65 living with dementia in the UK.<sup>18</sup>

As age is the greatest risk factor, the prevalence of dementia in the younger age range is lower – this is one of the biggest issues for people who do have young onset dementia, or have a family member who is living with this condition. The relative rarity of YOD has consequences for the health, social and financial support provided, and local services are likely to be more tailored to the needs of the oldest old with dementia.

## Higher prevalence of rarer dementias<sup>19</sup>

There is a higher prevalence of rarer dementias amongst younger people with dementia. Around one-third of people with young onset dementia have Alzheimer’s disease, whereas it is the most common diagnosis in the older population and the most studied and understood. Familial Alzheimer’s disease affects people between 35-55 years, which inevitably presents particularly difficult challenges for families and their support systems. People with learning disabilities are four times more likely to develop dementia and at a much younger age than the average person, (see the next section on dementia and disabilities). Vascular dementia affects about one-fifth of people with young onset dementia, whilst fronto-temporal dementias and alcohol-related dementia affect just over one-fifth of people with young onset dementia. Around one-fifth have even rarer forms of dementia. The symptoms experienced range widely in their presentation, and can include changes in personality, behaviour, mood, and memory.<sup>20</sup>

## Impact on needs of people with dementia and carers

It is important to recognise the different impact of dementia on the person and their family when experienced in mid-life. The needs are different and therefore the responses of health and social care, and the surrounding support network and community are different.

A diagnosis of young onset dementia is generally unexpected. It affects every aspect of life with increasing support required long-term. The ‘NeedYD-study’ in the Netherlands is the first study investigating the course of young onset dementia. Their findings suggest a person with young onset dementia lives at home for an average of 9 years.<sup>21</sup>

People with young onset dementia are more likely to have more active family responsibilities – such as children in education or increasingly dependent parents – and are more likely to need and want an active working life and income. Family members, usually spouses or partners, are more frequently in the position of becoming both the sole income earner, as well as ensuring the person with young onset dementia is appropriately supported.

People with young onset dementia can feel even more marginalised and isolated by the lack of support and the perception they have an ‘old age illness’. Due to the rarity of young onset dementia, people with the disease are less likely to meet other people in similar circumstances for peer or mutual support. They, and their family, are likely to feel stigmatised and isolated.

Tailored support is required to ensure the best possible well-being for a person with dementia and their family. Support which clearly identifies itself as for ‘young onset dementia’ helps awareness, and creates health and social support services which are flexible and adaptive. Additionally, it helps meet the varying needs of those with rarer/young dementias.

The route to diagnosis is usually longer in the younger person. The Needs-YD study recently found an average wait of 4.4 years, compared with 2.8 years for older people with dementia.<sup>22</sup> There are a number of reasons

diagnosis can take longer, for example, misdiagnosis as stress, depression, menopause and hormonal changes is common. Other reasons may be due to an individual less likely to attend the GP early; the GP may not be alert to the possibility of dementia in the young; the GP may lack clarity about the assessment needed of the route to diagnosis; or the GP may not be aware of the benefit of a diagnosis.

Commissioners and providers can best respond by ensuring that services are flexible, creative and individual in approach – this will prove more effective than setting up fixed or rigid programmes and places which are not as responsive as they will need to be.

## **Actions commissioners and providers can take, and questions they can ask of their current approach, to drive improvement**

- ▶ *In all public awareness campaigns, ensure that young onset dementia is explicitly included* – People living with early onset dementia should be included in coproduction of campaigns and campaign materials and in giving testimony in the campaign from lived experience.
- ▶ *Support GPs to have a basic understanding that young onset dementia exists* – GP training on dementia should include young onset dementia.
- ▶ *Ensure the local referral route for diagnosis is clear* – whether it is to neurology or memory clinics.
- ▶ *Genetic counselling should be available for those with familial risks.*
- ▶ *Ongoing support, counselling, information and education* – Once diagnosis is made, support, counselling, information and education must immediately follow, tailored to the issues faced by individual's living with young onset dementia and their family members.
- ▶ *Development of professional networks and expertise sharing* – Due to the low numbers and relative rarity, enable the development of professional networks and sharing of expertise amongst identified professionals to provide a resource for those professionals who will only very infrequently support a person or family with young onset dementia and do not have the opportunity to develop expertise and knowledge.
- ▶ *Peer support* – Seek opportunities to enable peer support between people and families affected by young onset dementia who are likely to be more dispersed than other individuals with dementia.
- ▶ *Support for Advance Directive planning.*
- ▶ *Support with retention of existing roles and age appropriate activities* – This includes socialisation, education and work aligned with the current capacity of the person living with young onset dementia and support with change where these are no longer tenable.
- ▶ *Access to advocacy support.*

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The traditional ways of supporting people to live well with dementia and to remain as independent as possible need to be tailored to the other disabilities they may have.

# Dementia and Disabilities

Lead Contributor: Gill Boston, National Care Forum, Voluntary Organisations Disability Group

## Introduction

In 1997 Tom Kitwood wrote about supporting people with dementia and took what we would now refer to as a 'personalisation' approach, arguing that the key to supporting people with dementia is to have deep understanding of that person as an individual, who has individual needs, a past, a family, a place in society. They will have some things in common with others who have dementia but will also have individual needs based on who they are that are not the same as others.<sup>23</sup>

These principles of personalisation, which include independence, respect, choice and control apply equally to someone with disabilities who develops dementia; however people with additional physical and learning disabilities face additional challenges simply because the greater the number and severity of the issues they face, the more difficult it is for the person to compensate for any one of them.

## Diagnosis

People with learning disabilities, physical disabilities and other additional unrelated physical and mental health problems face particular difficulties in obtaining a diagnosis of dementia. Diagnosis is important, not least because it is often the key to unlocking appropriate care and support (as Daniel's case study demonstrates) but also access to treatment that may prolong life and improve its quality. It is well documented that people with learning disabilities, in particular, often struggle to access appropriate treatment particularly for conditions considered to be unrelated to their learning disability, so early recognition and diagnosis is crucial.<sup>24 25 26</sup>

## Effect on Prevalence of Dementia

### *People with Learning Disabilities*

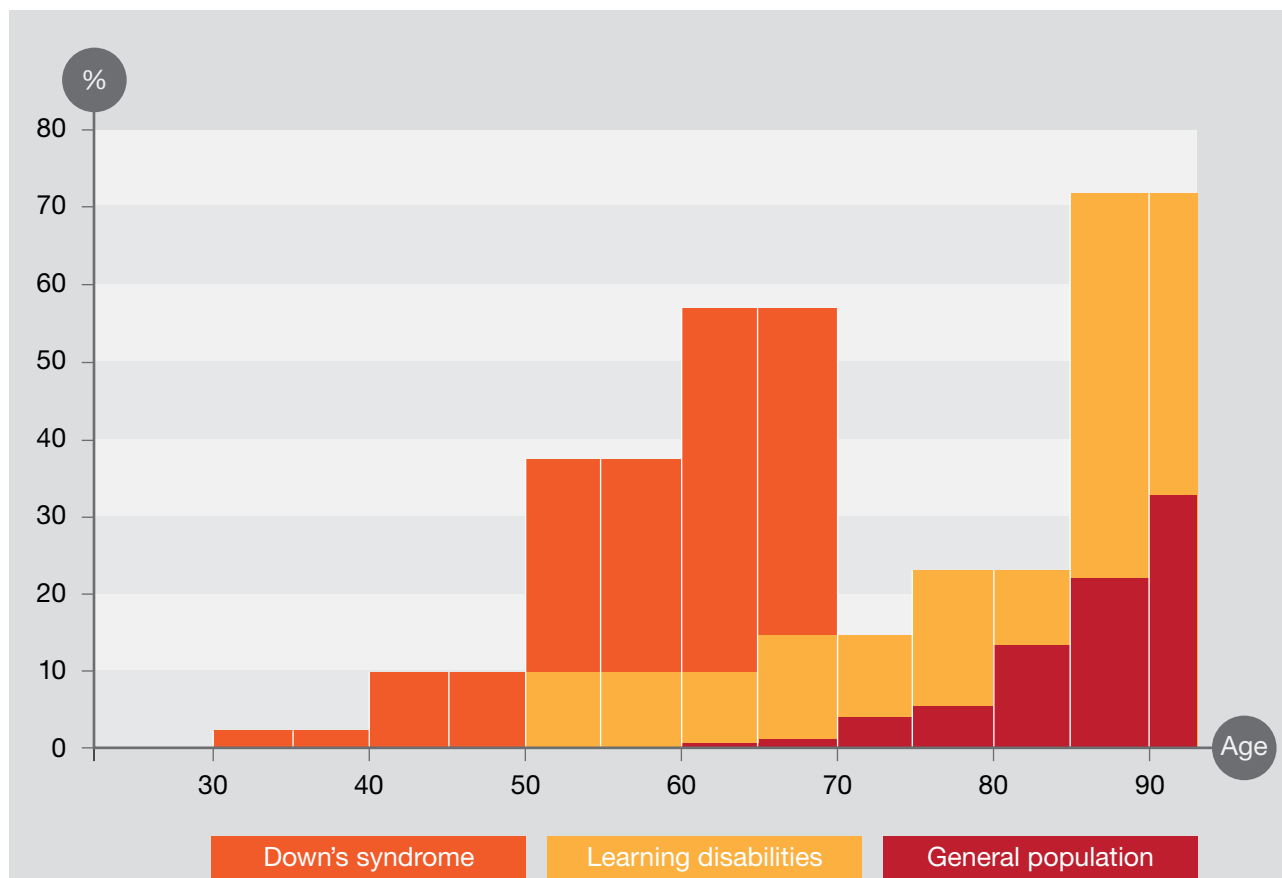
The last 20 years has seen a significant increase in the life expectancy of people with learning disabilities attributed to improvements in medical and social care. Understanding of how ageing affects people with learning disabilities and, in particular, their risk of developing dementia is only now becoming apparent.

Far more people with learning disabilities will develop dementia and at a much younger age than the general population and the progress of the disease will be more rapid.<sup>27</sup>

Figure 1 shows the prevalence of dementia in people with learning disabilities (which need to be read with some caution as, apart from Down's Syndrome, the statistics do not specify the range and type of learning disabilities affected and we know from other studies it is not necessarily related to IQ). People with learning disabilities who do not have Down's Syndrome are four times more likely than the general population to develop dementia. People with Down's Syndrome are at an even greater risk of developing dementia, almost all of whom will have Alzheimer's disease. The approximate numbers are shown in Figure 1.

# Dementia and Disabilities

**Figure 1:** Comparative rates of dementia - Down's syndrome, Learning disabilities, General Population.



Source: British Psychological Society (2009) *Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with intellectual disabilities who develop dementia*. Leicester: British Psychological Society.

Current thinking is that in later life all people with Down's Syndrome will develop the physiological changes associated with Alzheimer's disease but not necessarily the pattern of memory loss and the functional decline characteristic of dementia.<sup>28</sup> This is considered to be because the amyloid protein that causes the brain cell damage in Alzheimer's disease is found in the gene attached to the 21st chromosome, and people with Down's syndrome have an additional 21st chromosome.

## Impact on needs of people with dementia and carers

People with learning disabilities may present with behavioural changes rather than memory loss initially and this fact, together with "diagnostic overshadowing" – mistaking dementia symptoms for symptoms of the existing disability – mean people with learning disabilities are less likely to receive a timely diagnosis.<sup>29</sup> See Daniel's case study for an example.

In addition, people with learning disabilities are likely to have other health needs that may not be identified but could include high levels of unmet need as a result of health inequalities experienced in the health system.<sup>30 31 32</sup>

In terms of care and support, people with learning disabilities are also less likely to have partners or children who can care for them, and may well be carers for, or cared for by, their elderly parents – some of whom will have dementia themselves.<sup>33</sup>

# Dementia and Disabilities

Conversely, they are more likely to be already living in some sort of supported accommodation but it is likely to be a facility with staff that supports people with learning disabilities rather than specialising in dementia, and therefore their knowledge understanding of dementia and the needs of people with dementia is likely to be limited.<sup>34</sup>

## *People with physical disabilities*

There is a limited amount of literature available about people with disabilities and the effects of ageing, particularly in terms of the onset of dementia.

People with conditions which result in disability where dementia is a feature of the condition, such as Parkinson's disease, Huntington's disease, Picks disease etc., will develop dementia at a different rate and usually much younger than the non-disabled population.<sup>35</sup>

The issues for people who develop dementia, at what is considered to be a young age, are well documented in the section on Young Onset Dementia; however it is worth considering that the additional physical problems that some people with disabilities face can sometimes cause tensions in terms of the need for carers to reduce the risk of physical harm versus the need to retain skills and independence for those accessing support.

As in all areas of dementia, it is important to think about the rights of the person accessing support, including the right to take risks.

There is emerging evidence that a range of disabilities may affect the risk of developing dementia. For instance, the annual report of the Chief Medical Officer 2012<sup>36</sup> reported emerging findings of significantly greater risk of people with deafness or blindness reporting Alzheimer's disease or dementia. Action on Hearing Loss report results of a study that found people with mild hearing loss are twice as likely to develop dementia as people without hearing loss. The risk increases to threefold for moderate hearing loss and fivefold for severe hearing loss.<sup>37</sup>

The question is now being asked whether there are links to dementia from other types of disability and if the diagnostic overshadowing experienced by people with disabilities is masking a wider problem.

## **Impact on needs of people with dementia and carers**

Research findings aside, this information highlights that people with dementia have a wide and varied need for support. The traditional ways of supporting people to live well with dementia and to remain as independent as possible need to be tailored to the other disabilities they may have.

Two examples of this are as follows:

Design principles in planning care and support for people with dementia often rely on visual cues to aid memory, but if an individual has limited or no sight then design principles need to consider other ways of aiding memory (such as use of other sensory material and /or assistive technology).

In order to understand support plans, medication prescribed, or even bus timetables, information needs to be provided in an accessible manner. The new Accessible Information Standard<sup>38</sup> places a responsibility on both health and social care providers to provide information in a manner people can understand. In addition, the Equality Act 2010<sup>39</sup> puts responsibility on services to ensure reasonable adjustments are made for disability.

A talking timetable could support someone who has poor sight and struggles to retain complex information to access public transport, and a flag on a care plan or patient record can ensure that assumptions about

ability to understand are not made about someone with a hearing loss who may simply be struggling to hear what's being said to them.

## **Actions commissioners and providers can take, and questions they can ask of their current approach, to drive improvement**

- ▶ *Use a disability rights based approach* – Look at the environment to see what can be done to make life easier and fairer for people with dementia. This can include thinking about the application of the Equality Act 2010, the Accessible information Standard 2015, the Human Rights Act 1988, and The Care Act 2014.
- ▶ *Awareness raising of the effects of dementia and disability* – This should be aimed particularly at individuals, carers, primary care teams, social care teams, commissioners etc. to improve responses, anticipate need and help plan future support packages.
- ▶ *Use the local Joint Strategic Needs Assessment (JSNA)* – Assist future planning and identify people with early onset dementia, such as those with physical and learning disabilities and their family carers in local communities.
- ▶ *Develop tailored community resources* – Targeted to people with dementia and additional disabilities, these resources should support and develop a sense of citizenship that drive community presence and reduce isolation.
- ▶ *Support GPs and frontline workers to recognise signs and symptoms for early diagnosis* – Early diagnosis, and appropriate referrals, together with timely individual support packages considerably improve the quality of life for people and reduces the risk of, and delays admission to institutional care.
- ▶ *Tailored diagnostic pathways to improve early diagnosis for at risk groups* – In 2009 the British Psychological Society recommended baseline screening for all individuals with Down's syndrome while they are healthy to establish an accurate baseline of cognitive and adaptive function, alongside reactive assessment when concerns are raised. They also suggest services consider prospective monitoring for all people with Down's Syndrome starting at aged 40 or 50.
- ▶ *Consider particular needs of people with early onset dementia* – Consider the particular needs of people with physical disabilities who develop early onset dementia who are more likely to be in work, have children, have a rarer form of dementia and have heavy financial commitments such as a mortgage, factors which need to be considered when planning support packages.
- ▶ *Consider benefits of technology and modifications* – Consider how disability might affect people's ability to benefit from modifications to assist people with dementia. For example, design improvements that rely on sight. Also consider the use of assistive technology, particularly in the support needs of those with sensory loss.
- ▶ *Collaboration between various services* – Equip workforce across a range of services (learning and physical disability and older people's services) to be aware of the needs of people with disabilities and dementia and to make adjustments to their practice to meet them.



# Case study Daniel

Provided by NCF/VODG and Salford Health Matters

Daniel is a 64 year old man with Down's Syndrome who lives at home with his elderly parents (both in their late 80s). Eight months ago, he presented with his cousin as a new patient at his doctors surgery. The cousin described quite severe behavioural changes saying Daniel was aggressive, irritable and depressed. In addition, he was becoming forgetful but that wasn't seen as significant or an issue that needed dealing with. The behavioural changes were considered to be related to the Down's Syndrome and other underlying illnesses were not considered.

The GP referred Daniel to the community learning disabilities team for assessment and support, but he did not meet their criteria for a service. The GP then referred him to a psycho geriatrician who would not see him because he was not old enough (service only sees people over 65).

His GP was unsure of what else to do to offer support and was discussing it with an Advanced Nurse Practitioner (ANP) in the practice who, by chance, had a cousin with Down's Syndrome who had severe dementia, and had unfortunately since passed away from the disease. The ANP suggested he refer Daniel to the memory clinic as his symptoms could be related to dementia. Daniel was referred to the service and diagnosed with dementia and now he and his family are eligible for and receive a full care and support package.

Retrospective examination of Daniel's case notes reveal he has been experiencing behavioural changes for which he visited his GP for a number of years and these changes had not been considered to be anything other than an integral part of his Down's Syndrome. It was only when they became severe (and he changed his GP to Salford Health Matters) was any support offered to the family.

This small case study highlights a number of issues that are as follows:

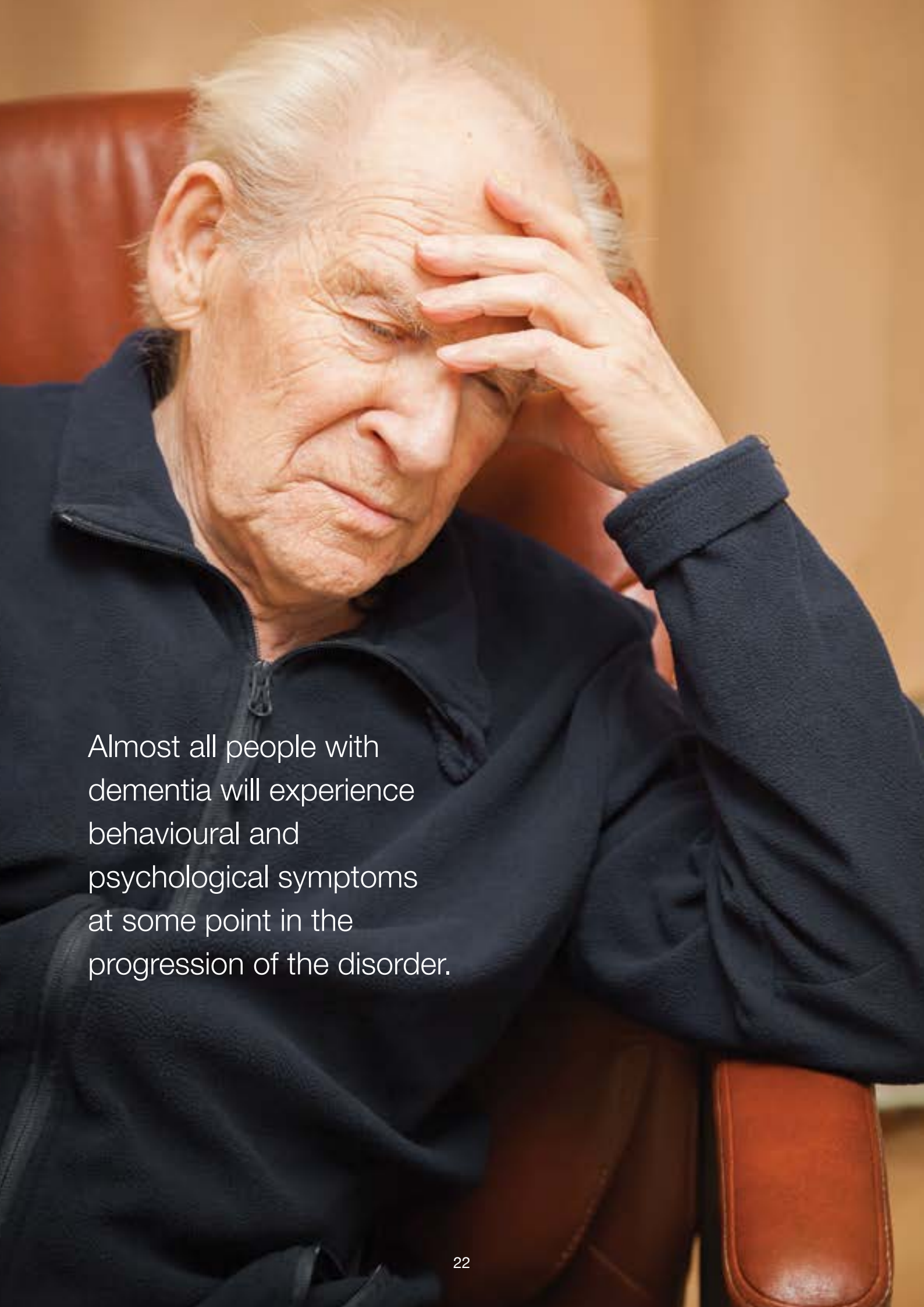
- *Diagnostic overshadowing* - This was clearly an issue here and certainly played a part in the length of time it took to recognise the problem and react appropriately.
- *Lack of knowledge and understanding of people with Down's Syndrome who develop dementia.* - The fact that Daniel was referred to the memory clinic was a matter of luck rather than judgement, if the GP hadn't gone the extra mile and spoken to that particular ANP it's unlikely he would have made the connection and subsequent referral to the memory clinic.
- *The vulnerability of this family* - the carers are in their late 80's and if Daniels aggression becomes physical, they could be at risk and this then becomes an adult safeguarding issue.



# Dementia and Disabilities

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Almost all people with dementia will experience behavioural and psychological symptoms at some point in the progression of the disorder.



# Mental health and dementia

Lead contributor: Mental Health Providers Forum

## Introduction

As all forms of dementia affect memory, language, processing, understanding and judgement, an adverse impact on mental health and wellbeing is likely. In addition symptoms and expressions of some mental health conditions are similar to some of the symptoms and expressions of certain forms of dementia. Lack of attention to worsening mental health can increase the likelihood of more rapid deterioration.

The Department of Public and Primary Care at the University of Cambridge undertook a study looking at mental health and dementia in 2009. Their findings suggest that almost all people with dementia will experience behavioural and psychological symptoms at some point in the progression of the disorder. In interviews with 2637 people (587 with dementia) they found participants with dementia experienced approximately three times the rate of depression, four times the rate of apathy, four times the rate of hallucinations, and almost 3 times the rate of agitation as participants without dementia.<sup>40</sup>

## Effect of prevalence on dementia

Studies have shown that up to half of people with dementia also have depression.<sup>41</sup> A number of other studies have suggested a relationship between psychological factors and the onset of dementia; however due to the lack of research and difficulties in establishing relationships, further research is required.<sup>42</sup>

## Impact on the needs of people with dementia and carers

### *Depression and Dementia*

The relationship between dementia and depression is complicated by many of the symptoms of dementia and depression being similar. On occasion someone who is depressed may be misdiagnosed as having dementia. A person with dementia may also become depressed.<sup>43</sup>

Individuals dealing with both will be struggling with two sets of difficulties and may be more confused and have greater memory loss. The double experience may also result in more extreme behaviour and/or aggressive reactions. It may be more difficult for GPs to accurately diagnose depression in someone with dementia due to the similarity of symptoms. Depression can occur with all forms of dementia but is most common with Parkinson's or Vascular dementia.<sup>44</sup>

Some of the clearest differences between depression and dementia are:

- Depression usually develops more rapidly
- Speech problems are more common in dementia than depression
- A person with dementia is more likely to mask or cover up memory loss
- Memory and judgement issues can improve with recovery in a person with depression but are likely to deteriorate in a person with dementia

Depression is often experienced by those caring for people with dementia, and carer assessments and respite reviews should be in place so that appropriate support is offered.

### *Anxiety and Dementia*

Anxiety is often experienced in conjunction with depression. The prevalence of people with dementia experiencing severe anxiety has formed the basis of several recent studies and results. Whilst they range from 5% to 21%, all agree that it is a significant proportion to generate attention and consideration by commissioners.<sup>45</sup>

# Mental health and dementia

Feelings of frustration and loss, common with the onset of the early stages of dementia, have the potential for increasing feelings of anxiety. People may feel unsure and unsafe and may worry about being left alone. Hoarding is quite a common reaction and can build up gradually. For instance, having multiple stores of similar objects in different places can begin as a sensible memory self-management strategy.

In the later stages of dementia, chemical changes in the brain may increase bouts of anxiety and depression.<sup>46</sup>

## *Psychosis and Dementia*

Psychosis often develops in people living with dementia as a feature of the progression of the condition and can be expressed through delusions, aggression, hallucinations, apathy and sleep disturbance. These behaviours can be particularly distressing for both the individual and their carers and may result in a break down in family structures when family members feel unable to provide the necessary support. There are often environmental factors contributing to the increase of psychosis for individuals who have dementia and can be related to necessary change. Anti-psychotic medications coupled with attention to the social needs of the individual and their family members may be helpful. Carers may need reassurance as to the non-intentional nature of the individual's comments or actions particularly when they may be the target. They may also need attention to their own support needs and healthcare. Both the individuals and carers can be offered coping strategies that may be of some help.

## *Carers*

Carers are under tremendous pressure at all stages of the progression of dementia, and their health and support needs should be separately assessed alongside those they are caring for. In 1998 The Mental Health Foundation produced a Carers' Checklist as a simple outcome based tool for people with dementia and their carers that is still being used effectively.<sup>47</sup> The Carers' Checklist positions carers emotional and social needs alongside wider needs, such as physical and financial needs.

## **Actions commissioners and providers can take, and questions they can ask of their current approach, to drive improvement.**

- ▶ *Consideration should be given to holistic treatments* – talking therapies can be helpful in addressing a range of mental health problems particularly in the early onset stages of dementia.
- ▶ *Understanding of difference between dementia and mental health* – As well as dual treatment for co-morbid conditions, attention should be given to the differences between dementia and various mental health conditions despite similar expression. For instance depression is likely to develop more quickly than dementia.
- ▶ *Ensure that full physical healthcare needs are assessed and addressed*, as they are often overlooked and can exacerbate other conditions.
- ▶ *Consideration should be given to diet, activity and basic needs* which may be overlooked and impacting.
- ▶ *Full carer assessments and support for carer's physical and emotional health* should be considered at all stages of progression of dementia for loved.
- ▶ *Nondrug options* for the management of agitation, anxiety or depression might include aromatherapy, multisensory stimulation, music therapy, animal-assisted therapy, massage, cognitive behavioural therapy (sometimes involving carers), reminiscence therapy and exercise.

# Case study Gene

Provided by Mental Health Providers Forum

Gene, a well-respected university professor aged 59 and divorced with two grown children, had begun to have issues with memory loss. He did not immediately recognise the problem, and as he lived alone there was no immediate attention given.

As misplaced items and forgotten appointments became regular, Gene began to be suspicious of family members and visitors to the household, believing that they must be stealing from him. Some of his relationships began to break down including a very important one with his oldest son, Don, whom he suspected was breaking into his home and stealing. He banned Don from visiting his home.

As he had been particularly close to his father previously, Don became seriously depressed at the loss of relationship and his inability to communicate with his father due to the contact withdrawal. As this began to affect Don's work and ability to function he attended the GP and was prescribed anti-depressants.

Gene told his daughter Penny that Don was still breaking in, and that he saw him scaling walls and appearing through the light fixtures. He continued to believe that Don was moving and stealing items. Penny agreed that some things were

spiritual and could not be explained. As Gene became increasingly convinced about the break-ins, his anxiety grew and he became very fearful. However any suggestion that he made to family members that he might be becoming forgetful was immediately followed with reassurance that it was quite normal.

After falling over a pavement cobble one day, and badly breaking his leg, Gene was admitted to the local hospital. It became apparent to attending staff that Gene was experiencing memory issues and he was referred for a memory assessment.

After having a full assessment and diagnosis, Gene was able to accept that he was in the early stages of dementia. He was referred for talking therapies and also given some simple strategies to use in terms of remembering things around the house. As family members were made aware of the real problem they became much more supportive. Gene was also referred to social services for an assessment for practical support.

Don had been receiving support from a local mental health charity, who were able to offer support in re-building Don's relationship with Gene, and Don was then also able to support and visit Gene productively.

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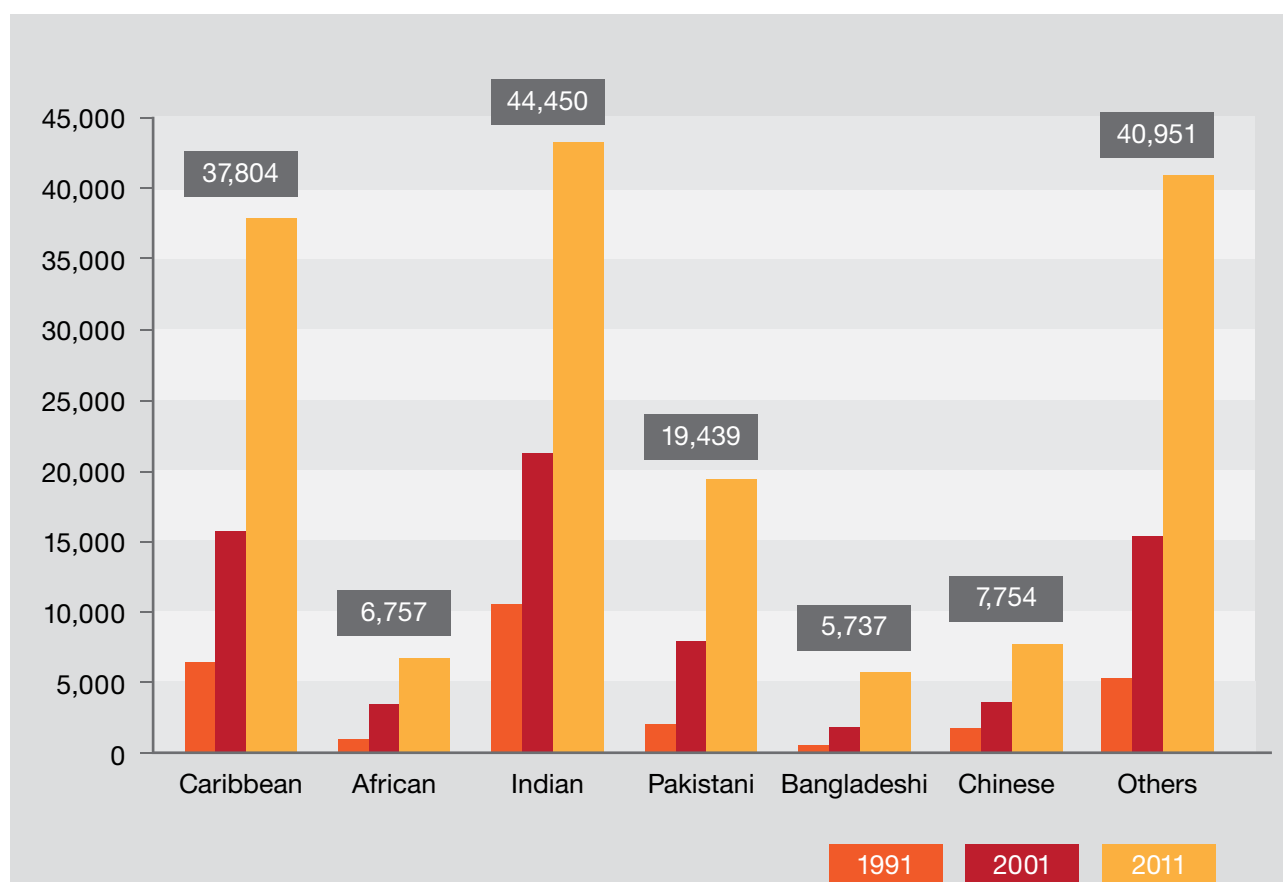
# Dementia and black and minority ethnic communities

Lead contributor: Kat Clayton, Race Equality Foundation

## Introduction

The black and minority ethnic population in Britain has previously had a younger profile in comparison to the majority white population, and subsequently, the attention given to the impact of age-related conditions such as dementia on these communities has often been limited. The number of older people from black and minority ethnic communities is growing rapidly. This shift in demographics presents a challenge for commissioners and providers of dementia services, with the need to monitor and predict local population shifts, particularly if services have not previously reached these groups.<sup>48</sup>

**Figure 2:** Black and minority ethnic people 75 years and older from 1991 to 2011.



Source: Chart developed by Butt, based on Simpson (2013)<sup>49</sup>

## Perceptions of dementia within black and minority ethnic communities

For some black and minority ethnic communities, the experience of dementia may be entirely new: many minority ethnic families migrated to the UK at working age, meaning they did not grow up with older relatives around them. Furthermore, in many communities, life expectancy in the UK may now significantly exceed that in their country of origin, increasing the likelihood both of dementia developing and of carers witnessing the effects of dementia for the first time.<sup>50</sup>

Barriers to the access and engagement of black and minority ethnic communities with health and care services is well-documented, particularly in relation to mental health services where issues such as limited awareness or fear of mainstream providers or stigma may play a major role in preventing uptake.<sup>51 52 53</sup> For example, dementia may be seen as a punishment for behaviour in a past life (reincarnation) or where arranged marriages occur, a family member with dementia may be seen as having a negative impact on their child's marriage prospects.<sup>54</sup>

# Dementia and black and minority ethnic communities

Knowledge of dementia and dementia services appear to be limited in some communities and as a result, symptoms of dementia are often confused with ‘normal ageing’.<sup>55 56 57</sup> Chinese participants in focus groups, carried out by the Race Equality Foundation, reported that negative perceptions of dementia were also frequently linked to translated or misunderstood terms, including “dull witted disease” or “lost intelligence disease” or “demented” (from African-Caribbean participants in the Race Equality Foundation focus group). There was some suggestion that those with dementia were more likely to hold negative views of dementia, while carers were willing to take on new information and try to help those they care for in their understanding of it.

However, it appeared many participants of the focus group were unsure where or how to find information about dementia, a problem exacerbated by language barriers, particularly amongst older people who may have lost cognitive skills. Furthermore, problems with accessing online information in community languages for some meant that there was an almost total reliance on community sector organisations to support their navigation of the system.

## **Effect on prevalence of dementia**

It is estimated more than 40,000 older minority ethnic people may now be living with dementia.<sup>58</sup> There is also a growing body of evidence to suggest that the prevalence of dementia is greater among African-Caribbean and South Asian UK populations and that earlier onset may occur amongst some ethnic groups, including Gypsy-Traveller and African-Caribbean communities.<sup>59 60</sup> In the case of African-Caribbean communities, a lower age of onset has been associated with the increased presence of risk factors for vascular dementia, such as hypertension. Some ethnic groups may also have a demographically older population, including Jewish and Irish populations, meaning that the prevalence of dementia may be higher.<sup>61</sup>

## **Impact on needs of people with dementia and carers**

A lack of awareness about dementia or problems relating to stigma mean that black and minority ethnic individuals with dementia will often present at a more advanced stage than other members of the population. Likewise, there is evidence that care professionals may fail to accurately diagnose dementia amongst older people from black and minority ethnic communities<sup>62 63</sup> or that the tests used in assessment and diagnosis may “lack validity because of cultural bias”.<sup>64</sup> David Truswell<sup>65</sup> has argued that spending on outreach services to increase awareness and understanding of dementia in minority ethnic communities could have significant financial benefits, as it would allow the gradual uptake of community or residential care rather than costly emergency service provision when individuals present at “crisis point”.

There are a number of expectations and cultural stereotypes surrounding caring responsibilities in black and minority ethnic groups. Whilst there have been significant challenges to the view that “they look after their own”, evidence suggests that minority ethnic carers are more likely to be isolated from mainstream services<sup>66 67</sup> and are still more likely to view dependence on statutory services as a source of shame.<sup>68</sup> The focus groups carried out by the Race Equality Foundation with Chinese older people found a pervading belief that loved ones will be isolated in residential settings or will be the only person from their ethnic background. Combined with the concept of “filial piety” in Chinese culture, the fear that the cultural and mental health needs of their family members will not be met by mainstream services may put carers under emotional and physical pressure. Likewise, the duty to care is apparent in Islam, Hinduism and Sikhism. Rauf<sup>69</sup> describes carers who saw the challenges of caring for a relative with dementia “as a test from God” that would be failed by dependence on outside services.

However, it is important that service providers do not generalise about the ability or willingness of black and minority ethnic carers to support for family members with dementia, either across or within different ethnic groups.<sup>70</sup> In many families, difficulties may exist when reconciling the needs and expectations of older people

with those of their families: older people may expect to be looked after by their extended family, while families may struggle to juggle care, work and other responsibilities.

## **Actions commissioners and providers can take, and questions they can ask of their current approach, to drive improvement**

- ▶ *Patient-centred, personally tailored approaches are vital* – This should include providing support that takes account of needs that may arise from culture or faith such as diet, hair/beauty care and other aspects of personal care. It is likely that this will be critical for the wellbeing of carers too, as poor or inappropriate treatment may limit uptake or raise issues of guilt or shame.<sup>71</sup> Improved training across the care pathway could reduce late diagnosis and ensure that individuals are better supported throughout their treatment. The use of “community dementia navigators”<sup>72</sup> or link nurses<sup>73</sup> may provide a practical and cost-effective method of supporting individuals with dementia and their carers from particular communities to find their way around the health and social care system. Arguments for and against the need for staff to have a similar background to their patients are long-running (with the risk that ‘ethnic matching’ may “import negative stereotyping of dementia from the culture of origin into the care relationship”<sup>74</sup>).
- ▶ *Language barriers, limited knowledge and fear of services are perhaps the main barriers to early diagnosis* – Health and care professionals should be sensitive when informing carers and patients about diagnosis, even when patients are able to speak some English or when interpreters are used. The appropriate use of interpreters from the beginning (including correct use of terminology and dialect) is crucial to a better patient experience, to avoid shame or fear and to help patients and carers to accept diagnoses and treatment options. Problems may be amplified where both staff and clients do not have a good grasp of English, as this can act as a ‘double-barrier’ to effective communication.
- ▶ *Communication with family members* – Regardless of language barriers, it is essential that staff communicate properly with family members throughout the care process, ensuring that they are kept well informed about decisions relating to hospital discharge, residential care, medication, and so on. Information resources should avoid jargon and should summarise cross-sector support, rather than giving individual leaflets for each service.<sup>75</sup> Videos may also be appropriate than written resources in some cases<sup>76</sup>, and professionals should also be aware of the role of body language in communication (i.e. whether eye contact, gestures, touching etc. are appropriate<sup>77 78</sup>).
- ▶ *Clear and open complaints processes* – Work with service users, carers, and representatives undertaken by the Race Equality Foundation suggests many black and minority ethnic service users are unaware of their rights to redress, and the fear that complaining will have a detrimental effect on their care appears to be common. Past or familial negative experiences, or fears of structural racism, mean that patients and carers may be apprehensive about using or complaining about services, which may affect their engagement with them, and the responsiveness of services.
- ▶ *Work with community service intermediaries* – Many older people in particular may feel more confident using black and minority ethnic-led voluntary and community services as go-betweens (both for information about existing services, but also to complain or inform them about their rights) and therefore commissioners should not neglect the role that such organisations can play, either in co-delivering services or for ensuring effective outreach and liaison with minority ethnic groups.
- ▶ *Support culturally appropriate voluntary and community sector groups* – Voluntary and community groups can also provide a key role in providing support and respite for carers.<sup>79 80 81</sup> However, although these groups may play an effective role in bridging gaps in care or access to services, the financial value of such “hidden services” should not be underestimated or go unrewarded, particularly at a time when many voluntary groups are losing resources and having to cut back services.



## Case study Chinese National Healthy Living Centre

Mrs B aged 90, is a widow, living on her own with dementia in North London. Her two granddaughters, who are her carers, live far away from her, outside London. Her dementia has caused her to revert back to speaking Cantonese, making it difficult to communicate with her granddaughters.

Due to her dementia, she had been leaving gas on, causing fire risks to herself and her neighbours. However, she is also very independent and does not accept help easily. Her carers have been very stressed trying to support her and sought help from CNHLC.

CNHLC made referrals to the local Alzheimer's Society and Social Services, co-ordinated meetings with all parties concerned, provided bilingual Cantonese interpretation/advocacy and support to all parties during the meetings.

As a result, Mrs B felt that her needs were understood, with CNHLC's help in interpretation and advocacy, her voice was heard.

Her granddaughters, whose Cantonese is not very good, were able to communicate with their grandmother through CNHLC's intervention and support. They were very pleased with the information received from Alzheimer's Society regarding how dementia impacts on her moods,

personality and useful tips on how to communicate with her and coping strategies. They were also invited to attend the 4 week Carers Information and Support Programme run by Alzheimer's Society, learning a lot about dementia, service provision and how to deal with finance/ legal matters for their grandmother. They understood her needs more and their communication and relationship improved a great deal.

With the help of Social Services, Age UK, and Alzheimer's Society, a personal alarm, befrienders, luncheon club, and meals-on-wheels services were arranged with support from CNHLC.

Eventually, after a serious fall at home on her own at night, Mrs B was placed under respite care, through Social Services, with the help from CNHLC who identified a nursing home run by Chinese nurses for Chinese elders.

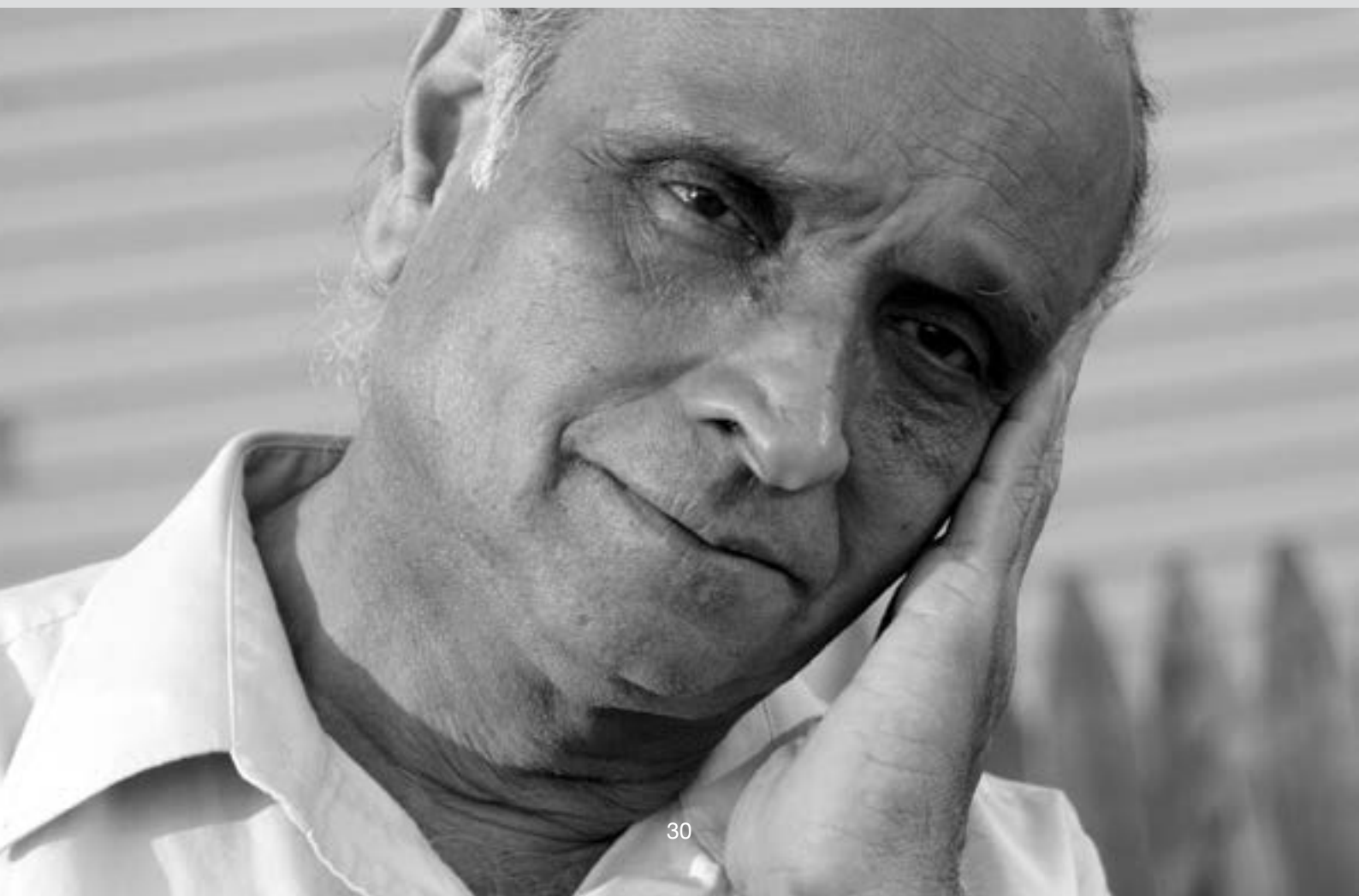
Both Mrs B and her carers are very grateful for CNHLC's help and support throughout this very traumatic period. CNHLC had also helped Mrs B in accessing GP, health and other relevant services.

She has now settled permanently in the nursing home following a review by social services and the family/ multi-discipline meeting.



# Dementia and black and minority ethnic communities


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Women with dementia have been called a 'marginalised majority' largely because dementia disproportionately affects women.

# Women with dementia

*Lead contributor: Marion Scott, Women's Health and Equality Consortium*

## Introduction

Women with dementia have been called a 'marginalised majority' largely because dementia disproportionately affects women;<sup>82</sup> a high proportion of whom are struggling to benefit from the policy aspiration of living well into old age. In the absence of a cure for dementia, focussing on research, treatment and support that takes into account sex and gender is a way of improving outcomes for women with dementia, and would also benefit men.

Gender is one of several factors and identities in women's lives which generate experiences that are shared and unique. Women may not always express concerns or experiences in a language of gender, but it remains a powerful key to explaining experiences and differences.

For an individual woman, gender impacts on her experience of dementia as a disease/condition, and the care she receives. Gender also influences the expectations and experiences of carers. This varies across cultures and communities.

Gender also affects the resources available to women with dementia. Through the life course, women as a group are financially disadvantaged (e.g. lower pay illustrated by the pay gap; lower pension income). Women are generally more dependent on state provision and arrangements, having less disposable income, but ironically, women's perspectives are also under-represented in decision-making about publically commissioned and funded health and social care (and in politics, policy, business and government generally). This is because there are fewer women involved, and leads to a failure to focus on women, equality and gender.

## Effect on prevalence of dementia<sup>83</sup>

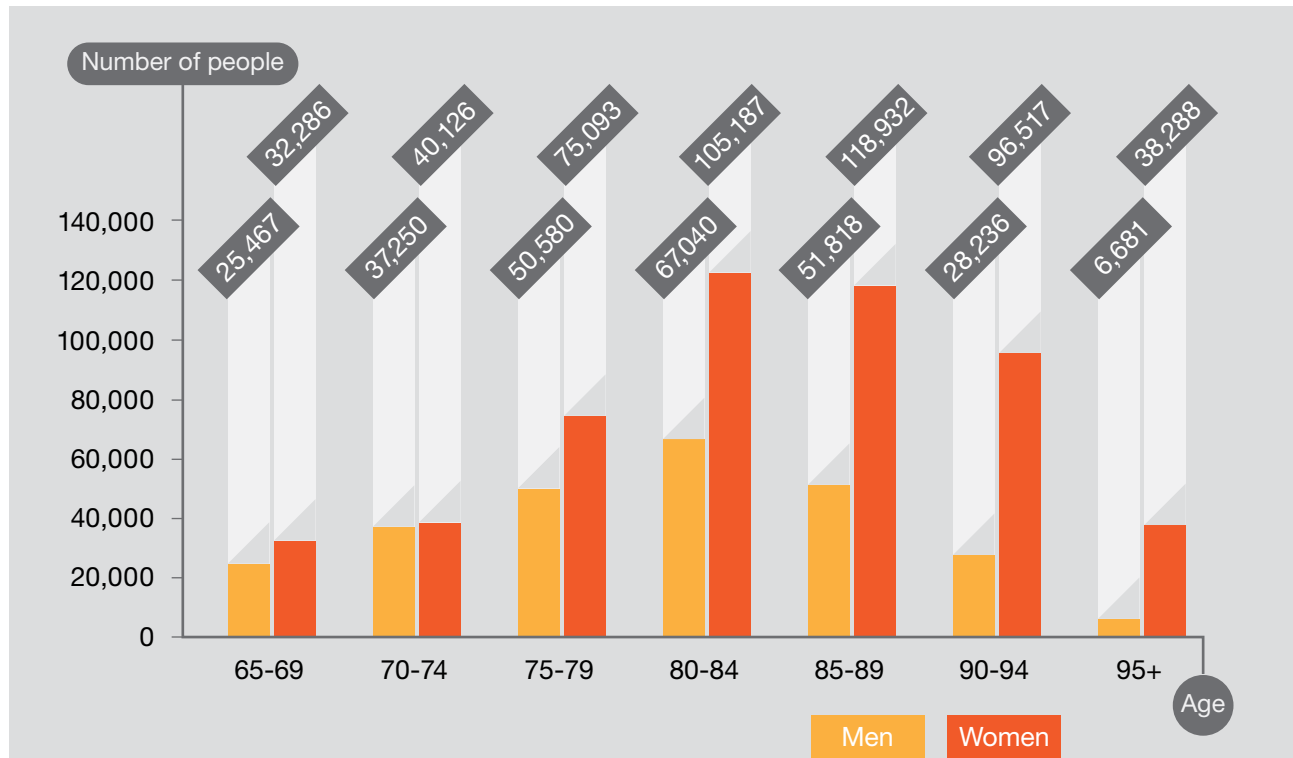
Approximately 500,000 women, with an estimated 15,000 from black and minority ethnic backgrounds, are living with dementia in the UK.<sup>84</sup> This makes up two thirds of the population living with dementia. For a breakdown of the number of people in the UK with dementia by age and gender see Figure 3. If we consider those suspected of having dementia but with no official diagnosis, then the numbers could potentially double.<sup>85 86</sup>

Women form the largest group of people in the age groups most at risk of dementia.<sup>87</sup> For example, 72.5% of people aged 90 or over in the UK in 2012 were women and dementia is age related, if not age dependent. The current average life expectancy is nearly 83 for women and around 79 for men.<sup>88</sup> On average women live 6.8 years after the age of 85.<sup>89</sup> An increasing number are now living to 100; however many older women will spend these last years in ill health and their life may be shortened by dementia.<sup>90</sup> See Figure 4 on the prevalence of dementia by age (women).

At 12.3% of deaths for women, dementia is the leading cause of death for women in the UK,<sup>91</sup> more than heart disease, stroke or the most common forms of cancer.

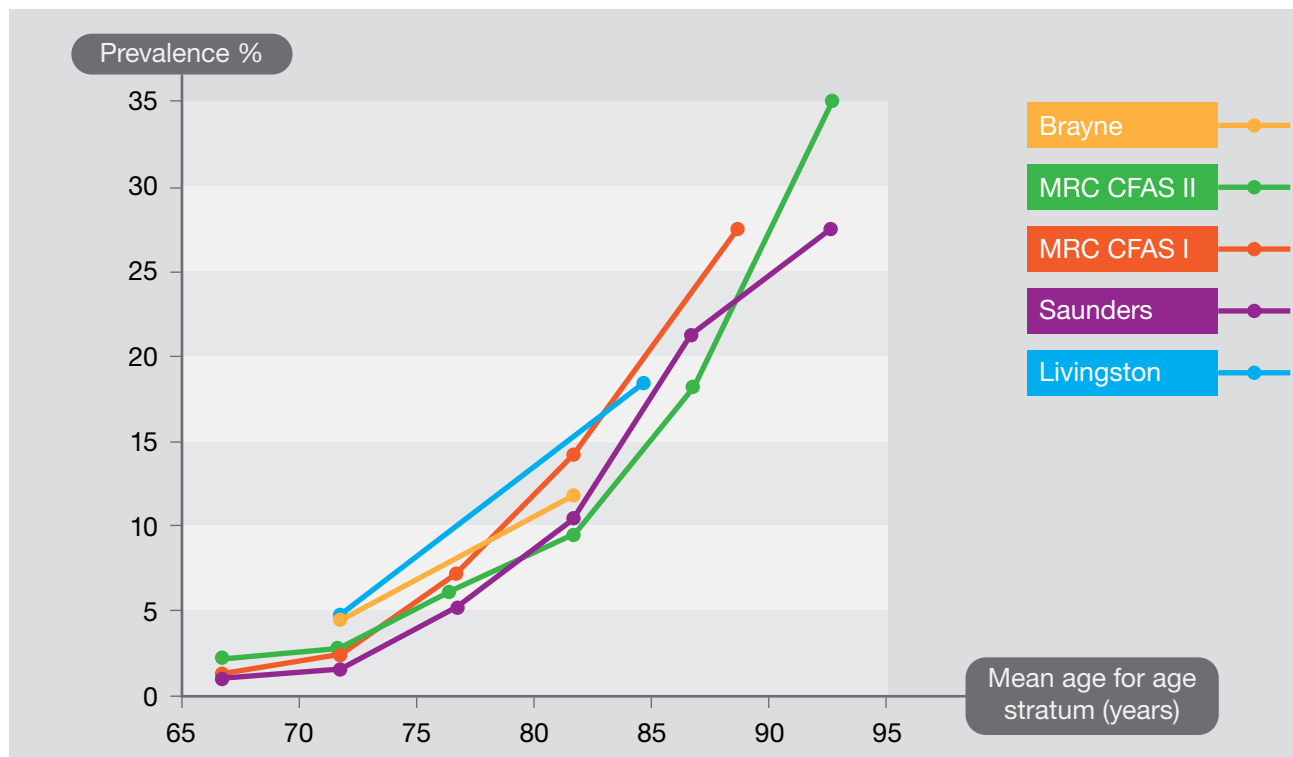
# Women with dementia

**Figure 3:** Number of people in the UK with late-onset dementia, by age and gender (2013)



Source: Alzheimer's Society (2014) *Dementia UK: Second edition* [www.alzheimers.org.uk/dementiauk](http://www.alzheimers.org.uk/dementiauk)

**Figure 4:** Prevalence of dementia by age (women) - UK studies



Source: Alzheimer's Society (2014) *Dementia UK: Second edition* [www.alzheimers.org.uk/dementiauk](http://www.alzheimers.org.uk/dementiauk). The prevalence estimates from the UK studies were compared with each other and contextualised with the Dementia UK 2007 Delphi consensus and with the Western European meta-analysis using age-standardization to facilitate the comparison.





### **Risk factors**

Age is currently understood to be the main risk factor disproportionately affecting women. In addition, there is some evidence that women are more at risk of Alzheimer's disease and some genetic causes for dementia are sex specific for women.<sup>92</sup> There have been studies exploring a range of associations and causes of dementia but more research is needed. For example, recent studies are considering the impact of reproductive hormone levels on dementia in women.<sup>93 94</sup>

### **Modifiable risk factors**

Modifiable risk factors refer to 'life style' and 'life course' factors that can help us understand the differences in expression of dementia and the different risk profiles in women and men. Factors relating to behaviour and to social determinants are potentially avoidable but they are widely influenced by gender and relations between women and men. These factors include diet, nutrition and lifestyle; mental health and well-being; violence against women; and socio-economic factors.

### **Diet/nutrition and lifestyle including physical activity**

There is some evidence that increased physical activity can reduce the risk of dementia, especially for women,<sup>95</sup> because it impacts on cardio vascular health, diabetes and mental health, which are all linked to dementia.

### **Mental health and well-being factors**

The relationships between depression, stress and other mental health conditions and dementia is discussed in the section on mental health.<sup>96</sup> Women, as a group are more likely to be affected by mental health issues due to the psycho-social impacts of their relative disadvantage. For instance, it is possible that living alone in older age, which happens more to women, may increase their risk of dementia.<sup>97</sup>

# Women with dementia

## Violence against women and girls

Women and girls experience considerable levels of gender and sexual violence over their whole life course<sup>98</sup><sup>99</sup><sup>100</sup> and older women are more likely to report violence than men.<sup>101</sup> Apart from stress, violence can involve neurological damage, which is linked to dementia.

## Socio-economic factors with gender elements

Financial disadvantage impacts on health, diet, exercise and well-being, as well as education and employment outcomes. Women overall earn less, are poorer in old age, and care for others more.<sup>102</sup> There are specific issues for groups of women such as disabled women, lesbians and women from particular black, Asian and other ethnic communities.

## Impact on needs of people with dementia and carers

Dementia as an illness is under researched and the effect of gender and sex on dementia is not well known. Increasingly, data collection is becoming more important and the drive in the EU to incorporate more gender and sex analysis is critical as it has the potential to improve outcomes for women.

Greater self-awareness, early, timely diagnosis, careful care planning, responsive health and social care services for each stage (early, advanced and end of life) can be improved through more feedback from users and by better use of findings from studies and research which have addressed gender differentials.

Substantial improvements in the quantity, quality and effectiveness of treatment and support could make a very significant difference to the lives and health equality of thousands of women with dementia and their unpaid carers. Women as a group, and minorities within a minority, experience more of the most severe symptoms.

More understanding of the sex and gender specificities in the expression of and response to medical and social treatments for dementia would benefit women.<sup>103</sup> For example, physical exercise has been found to benefit mortality in women, whereas men experience positive outcomes for cognitive improvement.<sup>104</sup>

Practical engagement with women with dementia has found that women are not used to being or reflecting on their position as women in a gendered society, reflecting a general tendency amongst women.<sup>105</sup> Nevertheless the associated research<sup>106</sup> and engagement have identified that gender and gendered experiences have the potential to add to our understanding and help create better responses.

Dementia sufferers need to be appreciated, recognised and responded to as individuals who have identities and experiences related to gender, ethnicity and sexuality.

## Informal care – the role of women and the impact of caring

Policy and practice guidance relating to health and social care tends to use gender-neutral words to describe carers and service users. This disguises how women are being affected as a group, and fails to show how and where the impact falls.<sup>107</sup>

Unpaid carers provide most of the care for people with dementia in the community, mainly women who make up around 60% to 75% of all carers.

Two and a half times more women than men provide intensive 'on duty care' for someone 24 hours a day.<sup>108</sup> Women are more likely than men to be providing essential, personal aspects of care. They are more likely to care for a long time and be caring for someone with advanced dementia.

20% of women carers have gone from working full time to part time and 18% have taken a leave of absence from work. 17% felt they had been penalised at work because of their caring duties.<sup>109</sup> Going part time or giving up employment to care, is likely to lower pension rights and income.

Caring for someone with dementia can have negative physical and mental outcomes, including stress, anxiety, depression, isolation, loss of a separate life with time for leisure, education or career, many of which are known risk factors for dementia.

Women's gendered role of caring remains powerful, in various forms and degrees in most communities. Deeply rooted gender norms and expectations do often persist and tend to disadvantage women or influence their experience.<sup>110</sup> External and internally held values can create an oppressive mix of guilt, duty and obligation and whilst caring can certainly bring enjoyment and satisfaction to some, nonetheless the caring/cared for experience often has an individual and a social context with complex, gendered patterns of behaviour.

## **Actions commissioners and providers can take, and questions they can ask of their current approach, to drive improvement**

- ▶ *Incorporate a gender lens* – Find ways to systematically use a nuanced gender perspective throughout the health and social care system and in relation to women's life course, to improve outcomes for all women affected by dementia - those caring or with the diagnosis.
- ▶ *Listen to lived experiences* – Consult with women with dementia and listen to their own experiences to create insight for commissioners and providers and ensure facilitators of consultations include gender analysis and awareness.
- ▶ *Offer better access to services* – Fund and facilitate interventions, day centres, hospitals and homes to respond to unmet needs around household management, food, self-care and accidental self-harm.<sup>111</sup>
- ▶ *Include women in decision-making* – Empower women and men who address the role of women and a gender perspective in the leadership and governance of health and social care affecting women with dementia, and women who care informally, or as paid workers. Implement the Equality Act and Public Sector Duties.
- ▶ *Take into account women's lifetime income* – The introduction of new business models for funding health and social care in older age has to take full account of women's lifetime income to avoid further disadvantaging or indirectly discriminating against women without effective support and services.<sup>112</sup>
- ▶ *Carer support and training* – Support informal carers, especially those providing the most intensive care, practically and emotionally, with well-designed financial benefits, addressing the limitations of the Care Act.<sup>113</sup> Train, remunerate and support paid carers and health workers to meet the challenge of dementia and avoid putting them in jeopardy of ill health and social inequality.
- ▶ *Create database of best practice* – Create a database and resource of best practice in dementia treatment and care for women that is relevant to commissioners, providers and decision makers, and addresses the life course, by looking at dementia-focused centres, institutions and individuals who have growing expertise or a sensitivity to gender and equality in England, Scotland and Wales.
- ▶ *Funding* – Fund specialist support and advice from the women's voluntary and community sector because gender based violence remains relevant for women living as carers or with a diagnosis of dementia.

## Case study Alice and Janet

Alice is a 56 year old British woman who cared for her mother, Janet, for 3 years before Janet died aged 83 in 2014. Alice suspected Janet had early signs of dementia in early 2011. Janet refused to acknowledge there was anything wrong, and was resistant to move closer to Alice, some 200 miles away from her home: *"My mother has always been a stubborn woman, very much a 'coper' and she just would not admit that she was not coping."*

Janet was eventually persuaded to move after she had a minor accident and when it became clear to her she could not cope alone. Alice and husband used Janet's savings to buy a local flat, which Janet moved into in November 2011.

Janet maintained she was able to cope and that there was nothing wrong with her. Alice negotiated Janet's attendance at a GP clinic under the guise it was for new residents, where she was given a dementia screening assessment. While it conclusively showed signs of dementia, Janet continued to maintain her 'wellness' and was unwilling to attend a local Psychiatric facility for a fuller assessment. After explaining the predicament to the Psychiatric Service who oversaw dementia diagnoses and follow-up health support, a consultant visited to give a formal diagnosis. For Alice this was a "huge relief" as she felt she had an ally beyond her husband. Indeed Alice was wholly positive about the support she received from community psychiatric services over the remainder of the time her mother was alive. *"I liked the way that if there was a concern I was able to ring up her [consultant's] office and.... I have to say they were very helpful indeed throughout the time that my mother was ill."*

Besides support from community psychiatric health services, support for Alice was limited because her mother had savings over £23, 000 and was not their "duty of care". Alice felt they were abandoned and left to fend for themselves. *"I found it very difficult and I felt very much out on my own! I was at the hospital and they said, 'what do you need to know?' and I said, 'what do I need to know?' And they said, 'what do you want to know?', and I said 'I don't know what I don't know!'"*

With no professional to draw upon and no friends or families with dementia experiences, Alice took to the internet and library where she eventually

became an 'expert' in dementia provision. She said she found some sources more useful than others: *"So it was online research, the NHS websites I found were appalling, but the Carers Concern, Age UK, the Alzheimer's Society, I just spent a lot of time trawling through their links to find things out."*

Alice also sought support from a Carers' Group but failed to find one that was available to her in the evening or on weekends, as weekday support groups were not an option during her working hours. Again, for Alice, it was an example of how she was let down by provision: *"If you worked all week, full time, it is bad enough to arrange for your mother's appointments, let alone taking off time for yourself, it just doesn't work. Even if it was only one evening, for this sharing of information, sharing of knowledge and sharing of experience, I never had that because I never had the chance to get away."*

As time went on Janet's dementia symptoms became more pronounced and her communication skills deteriorated quickly; eventually meaning she was unable to talk. Alice felt that Janet began to channel her frustrations towards her (more than other people), manifesting in Janet throwing things at her and occasionally physically hitting her. As their relationship deteriorated, Alice arranged for more visiting paid carers and eventually live-in carers. Janet was always more accepting of help from people other than Alice and was generally respectful and responsive in her carers' company.

After a hospital stay in April 2014 (originally stemming from a urinary infection), Janet's health deteriorated quickly and, although she was able to return home, she died only several months later.


For Alice, while her experiences of community psychiatric support was there and highly appreciated, the important wider support and knowledge that she needed never was. While she is now a dementia expert, it was a difficult knowledge journey, one she feels people less able would not be able to make:

*"I am an intelligent person, what about someone who is not, who is a bit old, a bit infirm, perhaps reluctant to receive help? It's that interconnection between social services and NHS about who's doing what and what services are available, because you don't know what is out there unless they do that".*



# Women with dementia

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it might be assumed that dementia affects everyone equally, whatever their socio-economic status. However, there is evidence that this is not the case.

# Socio-economic status

Lead contributor: Imogen Blood, Joseph Rowntree Foundation

## Introduction

At first look, it might be assumed that dementia affects everyone equally, whatever their socio-economic status. However, there is evidence that this is not the case.

In this section we show that *prevalence* is higher in areas of greater affluence - while the *risk of developing* dementia at any given age is higher in the areas of least affluence.

The impact on the most deprived groups is also more severe, because they have greater difficulty in finding out about and accessing support or even drugs treatment, and in affording services or even basic necessities such as transport and heating.

## Effect on prevalence

Higher socio-economic status (SES) brings longer life expectancy and, since age is strongly associated with dementia, *prevalence* is likely to be higher in more affluent areas. However, the *risk* of developing dementia at any given age,<sup>114</sup> and the rate of dementia-related hospital admissions<sup>115</sup> are likely to be highest in more deprived areas.

There is evidence to suggest that low levels of education in early life, hypertension in midlife, and smoking and diabetes across the life course may all increase the risk of developing dementia in later life, though the exact mechanisms are unclear.<sup>116</sup> There is a relationship between each of these risk factors and SES.<sup>117 118</sup>

Marginalised groups may experience higher prevalence rates and require different pathways: audits by homeless sector staff suggest that 14% of their clients have 'serious memory problems'.<sup>119</sup> Diagnosis and treatment for members of this group with 'alcohol-related dementia'<sup>120</sup> may be contested. Moll<sup>121</sup> describes issues and good practice in relation to prisoners who have dementia.

## Impact on needs of people with dementia and carers

The Coalition on Charging<sup>122</sup> found that many receiving domiciliary care could not afford basic necessities after paying care charges. Since 2008, there has been a 23% reduction in public expenditure on older people's community care: a growing number have to use their own resources or go without care.<sup>123</sup> People with dementia may suffer a particular impact since much of the help they need will be classed as 'social care'.

Dixon et al.<sup>124</sup> highlight the risk of socio-economic disadvantage in accessing specialist treatment, since primary care gatekeepers are more likely to empathise with better off patients. Daker-White et al.<sup>125</sup> found that articulate, middle class people tended to be more successful at finding out about dementia services. Barrett and Savage<sup>126</sup> found that better-educated people were being referred more regularly to a memory service in Dublin. Cooper et al.<sup>127</sup> found that home owners with dementia are four times more likely to be prescribed anti-dementia drugs (ChEIs) than those who rented.

Utility costs can rise significantly when someone has dementia, since restricted activity can slow body heat generation and conservation.<sup>128</sup> ONS 2012<sup>129</sup> statistics suggest that this group may suffer a greater impact from fuel poverty. Where people with dementia cannot afford accessible transport, they may miss out on therapeutic leisure and social activities, such as time spent in green spaces.<sup>130</sup>

Many carers face financial hardship as a result of both reduced income and additional outgoings<sup>131</sup> and this can be even greater where there is early onset dementia.<sup>132</sup> Carers Trust<sup>133</sup> describes particular problems in relation to Power of Attorney or the financial abuse of people with dementia.





Rural carers may face social isolation and access to poorer services.<sup>134</sup> Transport, respite and domiciliary care services may be more expensive due to petrol costs and staff travel time and the impact of not being able to afford private transport may be more keenly felt than in cities.

#### **Actions commissioners and providers can take, and questions they can ask of their current approach, to drive improvement**

- ▶ *Commissioning of services* – there is scope for joint commissioning of services providing advice (see case study), support, welfare benefits assistance and/or transport to people with dementia on low incomes. Healthcare and other workers are in a good position to signpost for income maximisation, if they receive appropriate training.
- ▶ *Reduce SES inequalities* – public health initiatives that aim to reduce SES inequalities in smoking, diabetes and cardiovascular conditions may also reduce such inequalities in dementia; and could be included in awareness raising campaigns.<sup>135</sup>
- ▶ *Local analysis of dementia by SES/deprived areas* – Joint Strategic Needs Assessment (JSNA) should include analysis of dementia prevalence, diagnosis, referral and hospital admission by SES/ deprived areas. See NHS Norfolk<sup>136</sup> and Corner and Jackson<sup>137</sup> for examples.
- ▶ *Clinical awareness raising and monitoring* on possible socio-economic disadvantage in referral, prescribing, etc.
- ▶ *Qualitative research on range of socio-economic backgrounds* – qualitative research around dementia may be skewed towards the experiences of middle class people.<sup>138</sup> ensure that consultation, evaluation and involvement in relation to dementia hears voices from a range of socio-economic backgrounds.

## Case study Socio-economic inequality

Lewisham MindCare runs a Dementia Information and Support Service, which is jointly commissioned by Lewisham CCG and the London Borough of Lewisham. It is an integrated part of the Lewisham Dementia Pathway. MindCare's Dementia Advisers aim to reach out to the many diverse communities in the borough, linking those affected by dementia into existing services and sources of support.

There are high levels of deprivation in the borough, alongside some pockets of significant wealth. The vast majority of MindCare's clients are struggling to cope financially, and many have limited literacy. The service has taken the following practical steps to ensure they are accessible to all and to reduce socio-economic inequality wherever possible:

- The service is free and can be accessed directly or by referral, by phone, e-mail or through the Age UK high street shop where the service is based;
- Appointments are flexible, so if a carer works during office hours, the advisors can offer them an evening or Saturday appointment;
- The advisers assess holistically, asking about finances from the outset and supporting people to maximise their benefits;
- They provide a free weekly exercise class for clients at a local leisure centre and link people into other free or low cost services and activities locally;
- They work hard to find affordable and accessible transport to get people to appointments and groups. However, they report that this can be very challenging in London: memory problems are not included in the eligibility criteria for a taxi card and even the charge for using the local volunteer driver scheme can feel high to some of those who are dependent on benefits;

- They run a Reading Aloud group which attracts a lot of people who cannot read and/or come from minority ethnic backgrounds;
- They offer practical support to those with low levels of literacy and health literacy – this includes reading appointment letters, explaining conditions, treatments and systems;
- They provide advocacy and often make phone calls to other agencies on behalf of clients – many do not have the confidence and some cannot afford to make such calls;
- They refer people for the free assistive technology, which is available to Lewisham residents with a diagnosis of dementia, although some clients struggle to afford the landline needed to support telecare services.

The Advisers observe that the gap regarding access to services between rich and poor in the borough seems to be widening in the context of reduced spending on public services.

*“Those who can afford to buy in care and support have so many more options open to them; those who can't seem to be waiting for longer now to get a social work assessment and, when the care is provided, some people feel they have little control over it or are dissatisfied with increasingly short visits and high staff turnover”.*

*“We want to be able to work preventatively with people to prevent them reaching crisis point but getting support for those who have limited financial resources feels like an increasingly uphill struggle.”*

MindCare is the specialist dementia arm of Bromley & Lewisham Mind. Further information about the service is available at: [www.mindcare.org.uk/lewisham-services/](http://www.mindcare.org.uk/lewisham-services/) or by email at: [info@mindcare.org.uk](mailto:info@mindcare.org.uk)



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# Sexual orientation and gender reassignment

Lead contributor: Tina Wathern, The National LGBT Partnership

## Introduction

For Lesbian, Gay, Bisexual and Trans (LGBT) people, their carers, partners, friends and relatives, living with dementia (and all of the demands it requires) can be very stressful. Whilst some of the challenges are the same as those for heterosexual people living with dementia, there will be many challenges that will not be the same.

## Existing Services

Health and social care policy and practice is often underpinned, albeit unwittingly, by cisgender, heteronormative attitudes and behaviours (the assumption that all people are heterosexual and identify as the gender they were assigned at birth), meaning the needs of these groups are prioritised.

Therefore, heterosexuality is prioritised in normal daily living, both implicitly and explicitly, and LGBT carers and those receiving care have to fit their experiences into a framework based on heterosexuality as the default position.

The recent ASCOF (Adult Social Care Outcome Framework) LGBT companion document<sup>139</sup> surveyed a number of service users and commissioners about the effectiveness of dementia care post-diagnosis and found that:

- Nearly three quarters (73%) of respondents said that the service they provide or commission does not collect data for LGBT service users with dementia in relation to the effectiveness of post-diagnosis care, in sustaining independence and improving quality of life. A fifth said this was collected, and a further 7% were unsure.
- Respondents who gave further information had not considered monitoring sexual orientation or gender identity in this area.

As work from SCIE (the Social Care Institute for Excellence) shows, “commissioners and providers don’t often think about LGBT people when planning and delivering services, but this does not mean that LGBT people are not using services or do not want to use services.”<sup>140</sup>

## Impact on needs of people with dementia and carers

Older LGBT people are more likely to live on their own and be single than heterosexual people. They are also less likely to have family members and children and therefore have less support. Often, older LGBT people will have a family of choice around them. The concept of ‘families of choice’ is intended to capture the commitment of chosen, rather than fixed blood relationships.

This lack of traditional models of support leads to an increased need to use social care services for their support and help. However, research has shown that some older LGBT people feel that mainstream care homes and services would not be able or willing to meet or understand their needs.<sup>141</sup> Many also said they would feel uncomfortable with paid carers and care home staff knowing their sexual orientation. This response is often based on a fear of prejudice or hostility which may be as a result of discrimination they have experienced.

Real and perceived prejudice of care environments is significant in the debate about ‘coming out’ in care settings, and at a recent Dementia roundtable event<sup>142</sup> one contributor said:

*“People ‘disappear’ in residential care - their identity ceases to exist - not many people are ‘out’ in care.”*

The debate heard about the worry of being forced “back into the closet” in later life because of the attitudes of care staff.

# Sexual orientation and gender reassignment

Central to the successful care of older LGBT people with dementia is the role of the carer. However, responsibilities can become more difficult if there is a lack of recognition from care homes and other services that do not fully understand the nuances of sexuality and gender.<sup>143</sup>

Traditional support groups where people talk freely about traditional family models, husbands/wives/children may be places where older LGBT people feel out of place, and unable to be open about their lives. They may fear the response if they speak about their partner or family.

It is important to remember that older gay men and lesbians grew up at a time when being homosexual was illegal, and for gay men being 'found out' resulted in a number of judicial consequences. Therefore, their sense of identity is shaped in the context of homosexuality being unnatural, and hiding themselves in a protective survival mechanism. Some LGBT people may avoid seeking support and care from services, for these reasons, when they need them.

Older LGBT people with dementia may show signs of 'hyper-sexualisation' and, as their barriers drop, start making inappropriate sexual advances to same sex residents within the care environment and consequently their sexuality becomes more evident.

A contributor at the recent Dementia Roundtable commented;

Reduced inhibition sometimes caused by dementia was a concern, *"a fear of losing control over what people say and do."*

It is important that non-judgemental environments exist in these situations, and that care workers do not display homo/bi/trans phobia.

One of the issues raised by the Dementia Roundtable<sup>144</sup> was:



# Sexual orientation and gender reassignment

The mental anguish suffered by transgender people with dementia who “*have forgotten they transitioned or forgotten they’ve not transitioned, or they ‘cross-dress’ and staff just think they’re confused - but that’s just what they do to be themselves*”.

This situation may prove difficult if, for example, you are creating a book of reminiscence.

Older LGB&T people with dementia may need support when taking medication to manage their doses. Keeping their sexual orientation/gender identity secret may prevent them from taking medication properly even when they are aware of the additional support they may require. For older LGB&T people living with HIV, medication may be significant in their maintenance of a healthy life and this may be compromised by a reluctance to disclose.

Older transgender people experiencing gender reassignment may need to take hormone medication in order to keep their biological sex in line with their gender identity.

## **Actions commissioners and providers can take, and questions they can ask of their current approach, to drive improvement**

- ▶ *Health and Wellbeing Boards and local authorities* should work closely with CCGs to promote the integration of health and social care which recognises the particular needs of LGB&T people.
- ▶ *The Joint Strategic Needs Assessment* should explicitly consider the needs of the local LGB&T community in relation to care and support.
- ▶ *Commissioners* should use *equality impact assessments* which include sexual orientation and gender identity when planning for the needs of people with dementia.
- ▶ *Commissioners of social care* should use the data available to them to assess whether mainstream services they have commissioned are accessible to and appropriate for LGB&T people and if not consider the need to develop specific LGB&T support in their local area.
- ▶ *Providers of social care* should implement the published guidance, as referenced in the Resources section of the Adult Social Care Outcomes Framework, on becoming LGB&T-friendly providers and relate this particularly to people with dementia.
- ▶ *Promote the values of diversity and social inclusivity* – providers should ensure their services are inclusive and welcoming to LGB&T people with dementia by promoting the values of diversity and social inclusivity.
- ▶ *Service providers* should invest in *training materials and specialist LGB&T training* – that includes an overview of LGB&T terms, historical context and legislation changes.
- ▶ *Commissioners and providers* need to consider *identifying appropriate support groups* – An LGB&T person living with dementia will talk about memories and people that are influenced by their experiences as an LGB&T person. They may feel unable to express this and connecting them with other LGB&T people and support groups may help support their identity and confidence.
- ▶ *Advanced care planning* is particularly important for people from LGB&T communities who may have limited family support. The purpose of advance care planning is to let someone make choices and decisions in case there is a time they are unable to do this for themselves.
- ▶ *Important to ensure that in order to make a lasting change* any project aiming to empower LGB&T people with dementia is driven by LGB&T people with dementia.

## Case study LGBT Foundation

Gay Advice Darlington/Durham (GADD) worked with a care home in rural Durham to support the particular needs of a trans service user with dementia.

Sue is a male-to-female trans woman who transitioned in the late 1970s. She completed gender reassignment surgery in 1982 at the age of 42. At the age of 59 she was diagnosed with an Alzheimer's variant and managed to cope with the condition by herself for a number of years, but was eventually in need of 24 hour care and went into a care home.

Sue's medical history was known to her GP but not to the care home. Sue had no contact with family as they had rejected her at the time of her transition. As her condition progressed, Sue experienced confusion about her gender identity. The care home management became increasingly worried as Sue began to refer to herself as 'Cliff' for periods of time, and was distressed by her appearance and physicality during these episodes. These episodes became more frequent and the care home was at a loss as to how to cope with the situation.

A social worker at the care home contacted GADD for advice. GADD formed a partnership group between the local authority social services, Sue's GP, the care home and GADD. This approach allowed all agencies to share knowledge and skills to develop a care plan that reinforced Sue's identity and sense of self using memory books and personal sense of gender. The care home staff received awareness training on trans identities, including the impact of stigma and misgendering, especially during the episodes of regression. This enabled them to offer appropriate care and support to Sue.

Although sadly Sue's condition continued to deteriorate, the agencies working with her now had a better understanding of the specific issues she was facing and delivered more empathic care, which significantly improved her wellbeing and quality of life.

Healthcare staff at each agency had developed their knowledge and skills around LGBT people's needs, which will improve their future work and care provision for other LGBT service users.

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# Links, resources, and further information

## Overarching resources – person-centred care for people with dementia

- Age UK Knowledge Hub – Knowledge hub for all information relating to older people [www.ageuk.org.uk/professional-resources-home/knowledge-hub-evidence-statistics](http://www.ageuk.org.uk/professional-resources-home/knowledge-hub-evidence-statistics)
- Age UK's 'Living Life with Dementia' report [www.ageuk.org.uk/Documents/EN-GB/For-professionals/Health-and-wellbeing/Living\\_life\\_with\\_dementia.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Health-and-wellbeing/Living_life_with_dementia.pdf?dtrk=true)
- Age UK's 'Diversity in older people and access to services – an evidence reviews' research report by Jo Moriarty and Jill Manthorpe [www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Equalities\\_Evidence\\_Review\\_Moriarty\\_2012.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Equalities_Evidence_Review_Moriarty_2012.pdf?dtrk=true)
- All-Party Parliamentary Group on Dementia [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1583](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1583)
- Alzheimer's Society (2015) Dementia UK: Update [www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2)
- British Geriatrics Society - Fit for Frailty (2014) [www.bgs.org.uk/index.php/press/2954-fff-media](http://www.bgs.org.uk/index.php/press/2954-fff-media)
- Carer's call to action - Top 20 checklist of services supporting family carers of people living with dementia [www.dementiaaction.org.uk/carers/examples\\_of\\_services\\_and\\_support](http://www.dementiaaction.org.uk/carers/examples_of_services_and_support)
- Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. London [www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy](http://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy)
- Knapp, M, and Prince, M (2007) *Dementia UK: the full report* [http://alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2](http://alzheimers.org.uk/site/scripts/download_info.php?fileID=2)
- Matthews, F, Arthur, A, Barnes, L, Bond, J, Jagger, C, Robinson, L, et al. (2013) 'A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II,' *The Lancet*, 382(9902) [www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)61570-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61570-6/fulltext)
- Making it Real for People with Dementia – A resource to show how Making it Real can be a useful tool for commissioners, providers, families and communities to help ensure that people with dementia can live well and independently for as long as possible. [www.thinklocalactpersonal.org.uk/\\_library/MIR\\_dementia\\_FINAL.pdf](http://www.thinklocalactpersonal.org.uk/_library/MIR_dementia_FINAL.pdf)
- NICE (2006) Dementia: Supporting people with dementia and their carers in health and social care, *NICE Clinical Guideline 42* [www.nice.org.uk/guidance/cg42](http://www.nice.org.uk/guidance/cg42)
- NICE – Quality Standard for Supporting People to live well with Dementia [www.nice.org.uk/guidance/qs30](http://www.nice.org.uk/guidance/qs30)
- Principles of Caregiving - a chapter on Dementia – a very practical approach to caring for someone with dementia [www.azdirectcare.org/uploads/APDChap8-DementiaJan11.pdf](http://www.azdirectcare.org/uploads/APDChap8-DementiaJan11.pdf)
- Social Care Institute for Excellence Dementia Gateway: supportive information and resources for care workers, people living with dementia, and their friends and family. [www.scie.org.uk/publications/dementia/index.asp](http://www.scie.org.uk/publications/dementia/index.asp)

## Oldest people with dementia

- Age UK (2013) *Improving later life: Understanding the oldest old* [www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Improving%20Later%20Life%20%20WEB.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Improving%20Later%20Life%20%20WEB.pdf?dtrk=true)
- Association of Directors of Adult Social Services (ADASS) (2011) *Caring Conversations: Older carers and health – promoting wellbeing* [www.adass.org.uk/AdassMedia/stories/conversations%20oldercarershealthfinal.pdf](http://www.adass.org.uk/AdassMedia/stories/conversations%20oldercarershealthfinal.pdf)
- Boyle, PA, Buchman, AS, Wilson, RS, Yu, L, Schneider, J, and Bennett, DA (2012) 'Effect of purpose in life on the relation between Alzheimer disease pathologic changes on cognitive function in advanced age', *Archives of General Psychiatry*, 69(5), 499–504 <http://archpsyc.jamanetwork.com/article.aspx?articleid=1151486>
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- Portet, F, Ousset, PJ, Visser, PJ, Frisoni, GB, Nobili, F, Scheltens, PH, Vellas, B, Touchon, J (2006) 'Mild cognitive impairment (MCI) in medical practice: a critical review of the concept and new diagnostic procedure. Report of the MCI Working Group of the European Consortium on Alzheimer's Disease', *Journal of Neurology, Neurosurgery & Psychiatry*, 77(6), 714–718 <http://jnnp.bmj.com/content/77/6/714>

## Young onset dementia

- Young Dementia UK [www.youngdementiauk.org](http://www.youngdementiauk.org)
- Younger people with dementia Factsheets [www.alzheimers.org.uk/site/scripts/services\\_info.php?serviceID=101](http://www.alzheimers.org.uk/site/scripts/services_info.php?serviceID=101)  
[www.scie.org.uk/publications/dementia/living-with-dementia/young-onset-dementia/](http://www.scie.org.uk/publications/dementia/living-with-dementia/young-onset-dementia/)
- Needs-YD Study [www.ukonnetwerk.nl/sites/default/files/Christian%20Bakker%20proefschrift.pdf](http://www.ukonnetwerk.nl/sites/default/files/Christian%20Bakker%20proefschrift.pdf)
- Harvey RJ, Rossor M, Skelton Robinson M (1998) *Young Onset Dementia: Epidemiology, clinical symptoms, family burden, support and outcome* <http://web.kamogawa.ne.jp/~miyake/yod.pdf>

## Dementia and Disabilities

- Action on Hearing Loss (2014) 'Report of Chief Medical Officer comments on need to look more closely at the hearing loss and dementia link' [www.actiononhearingloss.org.uk/news-and-events/all-regions/news/cmof-report-highlights-need-for-more-research-into-hearing-loss-and-dementia-link.aspx](http://www.actiononhearingloss.org.uk/news-and-events/all-regions/news/cmof-report-highlights-need-for-more-research-into-hearing-loss-and-dementia-link.aspx)
- Alzheimer's Society - detailed webpage with links to a range of resources aimed at professionals and carers working with people with Learning Disabilities [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=103](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103)
- Down's Syndrome Association – Down's Syndrome and Alzheimer's Disease: A guide for parents and carers [http://dsagsl.org/wp-content/uploads/2012/11/ds\\_and\\_alzheimers1.pdf](http://dsagsl.org/wp-content/uploads/2012/11/ds_and_alzheimers1.pdf)

# Links, resources, and further information

- Improving Health and Lives: Learning Disabilities Observatory - 'Making Reasonable Adjustments to Dementia services for People with Learning Disabilities': This has some good information on resources and includes case studies of good practice. [www.improvinghealthandlives.org.uk/uploads/news/vid\\_19037\\_RA%20Dementia1908Final%20LD%20edit%20docxPHE-2013179.pdf](http://www.improvinghealthandlives.org.uk/uploads/news/vid_19037_RA%20Dementia1908Final%20LD%20edit%20docxPHE-2013179.pdf)
- RNIB dementia and sight loss resources - Contains basic information and useful tips for coping with dementia and sight loss [www.rnib.org.uk/eye-health-sight-loss-other-medical-conditions/dementia-and-sight-loss](http://www.rnib.org.uk/eye-health-sight-loss-other-medical-conditions/dementia-and-sight-loss)
- NICE - Parkinson's disease: Diagnosis and management in primary and secondary care [www.nice.org.uk/guidance/cg35](http://www.nice.org.uk/guidance/cg35)
- Information on how dementia can affect people with Parkinson's [www.parkinsons.org.uk/dementia](http://www.parkinsons.org.uk/dementia)
- Health Charter to support social care providers to improve the health and well-being of people with learning disabilities, [www.vodg.org.uk/health-charter/health-charter-home.html](http://www.vodg.org.uk/health-charter/health-charter-home.html)
- Pocklington Trust has published a range of resources on dementia and sight loss: [www.pocklington-trust.org.uk/researchandknowledge/publications/Dementia.htm](http://www.pocklington-trust.org.uk/researchandknowledge/publications/Dementia.htm)

## Dementia and black and minority ethnic communities

- Age UK's 'Fit as a Fiddle: Engaging faith and BME communities in activities for wellbeing' report [www.ageuk.org.uk/Documents/EN-GB/FaithGood%20Practice%20GuideWEB.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/FaithGood%20Practice%20GuideWEB.pdf?dtrk=true)
- All Party Parliamentary Group – Dementia does not discriminate report [www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=1186](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1186)
- Chinese National Healthy Living Centre – An overview of the Reminiscence Tea House project on dementia and the UK Chinese community [www.brad.ac.uk/health/media/healthmedia/Truswell-The-Reminiscence-Tea-House-Story.pdf](http://www.brad.ac.uk/health/media/healthmedia/Truswell-The-Reminiscence-Tea-House-Story.pdf)
- Clayton, K, Butt, J, Islam-Barrett, F and Gardner, Z (2013) *Dementia in black and minority ethnic communities: Meeting the challenge, Findings from a one day learning event from Age UK and the Race Equality Foundation* Age UK and the Race Equality Foundation [www.raceequalityfoundation.org.uk/resources/downloads/dementia-black-and-minority-ethnic-communities](http://www.raceequalityfoundation.org.uk/resources/downloads/dementia-black-and-minority-ethnic-communities)
- Hare, P (2014) *The Unique Challenges Dementia Presents for Black, Asian and Minority Ethnic Communities*, Joseph Rowntree Foundation [www.jrf.org.uk/blog/unique-challenges-dementia-presents-black-asian-and-minority-ethnic-communities-0](http://www.jrf.org.uk/blog/unique-challenges-dementia-presents-black-asian-and-minority-ethnic-communities-0)
- Truswell, D (2013) *Black and minority ethnic communities and dementia: Where are we now?*, Better Health 30, Race Equality Foundation [www.better-health.org.uk/briefings/black-and-minority-ethnic-communities-and-dementia-where-are-we-now](http://www.better-health.org.uk/briefings/black-and-minority-ethnic-communities-and-dementia-where-are-we-now)
- Memory Services Handbook - An electronic resource handbook for Central and North West London Memory Services: Dementia information for black, Asian and minority ethnic communities [www.cnwl.nhs.uk/services/mental-health-services/older-people-and-healthy-ageing/memory-services/](http://www.cnwl.nhs.uk/services/mental-health-services/older-people-and-healthy-ageing/memory-services/)

## Women

- Alzheimer's Disease International ADI (2015) *Women and Dementia: A global research review* [www.alz.co.uk/sites/default/files/pdfs/Women-and-Dementia.pdf](http://www.alz.co.uk/sites/default/files/pdfs/Women-and-Dementia.pdf)
- The Dementia Centre (2014) *Women and Dementia* <http://dementia.stir.ac.uk/blogs/dementia-centred/2014-08-06/womenand-dementia>
- Women's Health and Equality Consortium – A partnership of women's charity organisations who share common goals of health and equality for girls and women [www.whec.org.uk/wordpress](http://www.whec.org.uk/wordpress)

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