

# Dementia and equality – meeting the challenge in Scotland

Recommendations of the National Advisory Group on  
Dementia and Equality

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The recommendations outlined in this report have been put forward by the National Advisory Group on Dementia and Equality to address Commitment 16 of Scotland's second National Dementia Strategy 2013–16, and to inform the future dementia strategy of the Scottish Government.

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# Foreword

## Professor Graham A Jackson

Dementia was made a national priority by the Scottish Government in 2007, and since then we have seen the development of Scottish Dementia Strategies covering the periods 2010–2013 and 2013–2016. A third strategy is currently in development. Many groups have been involved in both the consultations and in the development of the strategies, including people with dementia and their carers.

There have been many improvements both in how dementia is conceptualised and in how diagnosis and subsequent support have been introduced. These initially focused mainly on early signs of dementia, that is, around diagnosis and support for people who were just starting to develop changes associated with dementia, and on care in acute hospitals. The third strategy is likely to have an increasing focus on people with dementia who require support in the later stages of their condition, particularly around long term care in hospitals and care homes, as well as issues around what is often termed palliative care.

However, one thing that has been in need of further development is the care and support, including diagnostic pathways, for people who have those characteristics protected by the Equality Act 2010. We know that many of these groups are under-represented in terms of the numbers of people diagnosed with dementia, and current services do not fit well with their needs. This was recognised in Commitment 16 of the second strategy (2013–2016), and the working group subsequently set up has produced this report as a result.

Prior to my current post I was a Consultant in Old Age Psychiatry, and Clinical Dementia Lead for Scotland's largest Health Board. In these roles I was very aware that certain populations were rarely seen at our clinics, and that when people from these groups did come to us, we were often unable to meet their needs in terms of providing services comparable to those provided to others.

Dementia is still associated with stigma, and so too are many of the protected characteristics. We need to change this in society and recognise equality as a human right. There is a pressing need to make these issues more visible and by doing so ensure that our health and social care services are able to provide high quality support to everyone with dementia in Scotland. We hope that this document will provide a basis for taking this forward.

**Professor Graham A Jackson**

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January 2016

## Executive summary

Scotland's second National Dementia Strategy 2013–16<sup>1</sup> identified 17 commitments underpinned by a human rights approach. The strategy highlighted five particular population groups with characteristics protected by the Equality Act 2010, where challenges might arise in the context of dementia:

- Age – younger onset dementia (under the age of 65 years)
- Race and ethnicity – black or minority ethnic (BME)
- Learning disabilities
- Lesbian, gay, bisexual and transgender (LGBT)
- Disability – sensory impairment

Commitment 16 of *Scotland's National Dementia Strategy 2013–16*, states that: 'We will undertake a brief piece of work focusing on the care pathway for these groups, through diagnosis and support, through treatment and care, taking account of the particular challenges for carers and family members with the objective of identifying what further actions are required to ensure that each of the key improvement areas – diagnosis, post-diagnostic support, care coordination – requires modification to take account of the needs of different groups.'

The recommendations outlined in the following report were compiled by the National Advisory Group on Dementia and Equality to address the requirements of Commitment 16.

However, Commitment 16 is concerned predominantly with the experience a person with dementia will have when coming into contact with the health and social care workforce. But it is important to acknowledge that there are many people, from a broad range of professions, organisations and communities – from family to faith leaders to dementia-friendly volunteers – who will influence that person's experience too. This guidance therefore applies equally to all those involved in the life of a person with dementia.

The recommendations consist of four key themes followed by specific recommendations for each of the population groups listed above.

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<sup>1</sup> Scottish Government. *Scotland's National Dementia Strategy 2013–16*  
[www.gov.scot/Resource/0042/00423472.pdf](http://www.gov.scot/Resource/0042/00423472.pdf)

# Recommendations

## Four key themes

### 1. Continue to raise awareness

Raising awareness and increasing understanding of signs and symptoms of dementia among all of Scotland's different population groups is fundamental to promoting early diagnosis. Further research and development work is needed within local communities of different population groups to develop culturally sensitive information about dementia and available services and to establish the most effective ways of raising awareness of dementia. This includes using appropriate terms, recognising that the word dementia does not translate into all languages or that it may not have meaning to a person with a learning disability.

Community connections, and the support of family and friends, need to be targeted as a key resource for both tackling stigma and encouraging early diagnosis and increasing quality of life within the community post diagnosis. Work undertaken in Scotland within different communities identified the importance of building up relationships and trust between the health and social care workforce, community workers and communities in order for discussion about dementia and the needs of the community to take place. We need to continue to recruit and build a workforce that is representative of the communities of Scotland.

### 2. Ensure robust services and support pathways

There is a need to continue to ensure clearly signposted, robust, culturally competent,<sup>2</sup> locally informed services and post-diagnostic support pathways for people from the protected characteristic groups with a diagnosis of dementia, their carers and their families. This is vital with respect to the new agenda of health and social care integration and key to a whole systems approach.

### 3. Ensure appropriate knowledge and skills

Essential to encouraging early help-seeking among different population groups with protected characteristics, and to providing a supportive post-diagnostic pathway, is

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<sup>2</sup> A culturally competent service is defined as 'a service which recognises and meets the diverse needs of people of different cultural backgrounds. This applies to every individual with a healthcare need. It includes, but is not limited to, making provision for religious and cultural beliefs such as worship, diet and hygiene requirements, catering for communication and language diversity and involving users in service development. A key part of cultural competence is ensuring that discrimination on the basis of culture, belief, race, nationality or colour has no role in the delivery of services'

Scottish Executive. 'Fair for All: Working Together Towards Culturally Competent Services' NHS HDL (2002) 51

the need for an individualised care approach that recognises all aspects of an individual's identity, such as age, disability, race, religion and sexual/gender identity. NHS Education for Scotland (NES) and the Scottish Social Services Council's (SSSC) 'Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers' outlines the knowledge and skills, behaviours and attitudes the workforce needs in order to provide this type of service, linked to quality of life outcome indicators and stages of the dementia journey.

The Promoting Excellence work programme will continue to develop as the evidence base for equality issues and dementia evolves. The aim is to ensure that the health and social care workforce in Scotland remains equipped with the knowledge and skills to deliver an individualised, culturally competent care approach.

## 4. Research

Further research is needed:

- to determine the most effective ways to raise understanding and awareness of dementia among different population groups
- to identify and evaluate the impact of culturally competent dementia friendly community approaches in increasing awareness of dementia and diagnosis rates
- to collect Scottish incidence and prevalence data in relation to people with protected characteristics and dementia, including homeless people and those within the prison population.

## Specific recommendations

Specific recommendations for each of the population groups run to some 50 items. Members of the National Advisory Group on Dementia and Equality, with specific expertise in each area, agreed to select three priority recommendations for each group for the purposes of this executive summary. The following list comprises just 16 of the 50 recommendations included in the full *Dementia and Equality – how do we get it right?* report.

## Socio-economic inequalities

### Recommendations:

- Ensure a personal outcomes approach<sup>3</sup> is followed at the time of diagnosis to support the person with dementia and their family. This includes signposting to other services – for example financial and benefit advice, employment,

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<sup>3</sup> [www.jitscotland.org.uk/action-areas/personal-outcomes/](http://www.jitscotland.org.uk/action-areas/personal-outcomes/)

housing and access to services where the person lives, including rural and remote areas of Scotland, if these are of concern.

## Age – younger onset dementia (under the age of 65 years)

### **Recommendations:**

- Increase understanding with the public, and the health and social care workforce around younger onset dementia issues, including rarer forms of dementia.
- Ensure each Health Board establishes and publishes clear diagnostic and post-diagnostic referral and care pathways.
- Develop services that are age appropriate including respite services, care at home and long stay care, to support individuals to continue to be active in communities and remain in their own home.

## Race and ethnicity (BME)

### **Recommendations:**

- Build close relationships and trust with different communities – recommend community workers, trained in dementia, to build up relationships and explore and develop appropriate ways of raising awareness of dementia.
- Provide services for people with a diagnosis of dementia and their families that are culturally competent.
- Use assessment instruments that are culturally sensitive and do not rely on literacy and/or fluency in English or are culturally biased.

## Learning disabilities

### **Recommendations:**

- Establish a baseline assessment of functioning for people with learning disabilities, and particularly for adults with Down's syndrome, against which to compare future suspected changes.
- Ensure access to appropriate assessment tools, for example the National Task Group Early Detection Screen for Dementia (NTG-EDSD) that can be used for the early detection of dementia, or other treatable conditions, in adults with a learning disability. A Scottish version has recently been published and complies with the Scottish Dementia Strategy 2013–16.<sup>4</sup>

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<sup>4</sup> <http://aadmd.org/ntg/screening>

- Adopt, for each area, a Learning Disability and Dementia Action Plan<sup>5</sup> and integrated care pathway incorporating end of life care planning to support the provision of high quality assessment, intervention and care.

## Lesbian, gay, bisexual and transgender (LGBT)

### **Recommendations:**

- Ensure workforce is informed and open: culturally appropriate care is about respecting and preserving the person's identity, who they are and their whole life history. Service providers who have had little contact with LGBT people need to access specialist sources of support for a LGBT person with dementia or their carer.
- Provide a safe space: concerns exist not just about the attitudes of staff, but also attitudes of other service users with dementia. A clear zero-tolerance policy to homophobic, biphobic and transphobic language and behaviour should be adopted to ensure the emotional, and sometimes physical, safety of LGBT people.
- Include proactively: it is important that publicity material regarding dementia and/or policy documents are pro-actively inclusive of LGBT identities. Provide prominence to policies relating to confidentiality.

## Disability – sensory impairment

### **Recommendations:**

- Increase workforce understanding of how best to support people with impairment or loss of sight or hearing and dementia.
- Require health and social care workforce to know there is a duty to provide information in accessible formats, such as using British Sign Language (BSL), in order to remove or minimise disadvantage.
- Use assessment instruments that are culturally sensitive and appropriately geared for people who have sight or hearing impairment or loss, including Deaf BSL users.

Executive summary, January 2016

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<sup>5</sup> British Psychological Society. *Dementia and People with Intellectual Disabilities*. Leicester, 2015.

# 1.0 Background

‘... If you get it right for **every person** with dementia you get it right for everybody.’

James McKillop, Scottish Dementia Working Group, January 2016

Dementia was made a national priority by the Scottish Government in 2007. The second National Dementia Strategy 2013–16<sup>6</sup> identified seventeen commitments underpinned by a human rights approach. The key outcomes for the dementia programme of work in Scotland include:

- more people with dementia living a good quality life at home for longer
- dementia-enabled and dementia-friendly local communities, that contribute to greater awareness of dementia and reduce stigma
- timely, accurate diagnosis of dementia
- better post-diagnostic support for people with dementia and their families
- more people with dementia and their families and carers being involved as equal partners in care throughout the journey of the illness.

The second National Dementia Strategy acknowledged that there are challenges and that different approaches may be required to ensure all of Scotland’s population has an opportunity to receive a timely, accurate diagnosis of dementia and post-diagnostic support both for people with dementia and their families. The strategy highlighted five particular population groups with characteristics protected by the Equality Act 2010, where challenges might arise in the context of receiving a diagnosis of dementia and post-diagnostic support:

- Age – younger onset dementia (under the age of 65 years)
- Race and ethnicity – black or minority ethnic (BME)
- Learning disabilities
- Lesbian, gay, bisexual and transgender (LGBT)
- Disability – sensory impairment

Commitment 16 of the Scottish Government’s current National Dementia Strategy 2013–16, states that: ‘We will undertake a brief piece of work focusing on the care pathway for these groups, through diagnosis and support, through treatment and care, taking account of the particular challenges for carers and family members with

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<sup>6</sup> Scottish Government Scotland’s National Dementia Strategy 2013–16  
[www.gov.scot/Resource/0042/00423472.pdf](http://www.gov.scot/Resource/0042/00423472.pdf)

the objective of identifying what further actions are required to ensure that each of the key improvement areas – diagnosis, post-diagnostic support, care coordination – requires modification to take account of the needs of different groups.’

NHS Health Scotland, the Scottish Government, the Care Inspectorate and Alzheimer Scotland have been working in partnership with key stakeholders to focus on evidence of effective interventions to raise awareness of dementia among different population groups with characteristics protected by the Equality Act 2010. Evidence has been reviewed from literature and practice in Scotland to produce these recommendations. The aim is to raise awareness and reduce stigma around dementia and to support culturally appropriate, timely diagnosis and post-diagnostic support to all of Scotland's population, including those newly diagnosed and entitled to the national post-diagnostic guarantee.

During 2015 the process to develop the recommendations included:

- A literature research: NHS Health Scotland published an evidence briefing paper ‘Dementia and equality’.<sup>7</sup> The briefing paper includes information from a diverse range of literature and practice with a focus on evidence of effective interventions to raise awareness of dementia among different population groups with characteristics protected by the Equality Act 2010.
- An advisory group: A National Advisory Group on Dementia and Equality was established, comprising a broad range of stakeholders (Appendix 1). Its purpose was to consider the issues that different equality groups can experience in Scotland around diagnosis of dementia and awareness of dementia within the different communities of interest. The group met four times and took evidence from the NHS Health Scotland evidence briefing paper, practitioners, academics and people living with diagnosis of dementia and carers about key issues, practice and experiences in Scotland.
- Focus groups: Alzheimer Scotland was commissioned to undertake a series of ‘listening groups’ and one-to-one discussions to explore with people from different communities of interest the issues, barriers, opportunities and experiences of receiving a diagnosis of dementia.
- A workshop: Scottish Government hosted an Equality Impact Assessment (EQIA) workshop in July 2015 with key stakeholders (Appendix 2). A report from this workshop highlights key themes emerging about how to better support services to deliver a timely diagnosis and dementia care to everyone in Scotland.<sup>8</sup>

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<sup>7</sup> White J. *Dementia and Equality Briefing Paper*. NHS Health Scotland: Edinburgh; 2015.

<sup>8</sup> Scottish Government. *Scotland's National Dementia Strategy 2013–16 Equality Impact Assessment Report*. Edinburgh; 2015.

## 1.1 Overarching principles for recommendations

The National Advisory Group on Dementia and Equality has made recommendations using overarching principles drawn from four key sets of standards and principles important in the agenda of dementia and health and social care: Standards of Care for Dementia in Scotland (2011); Draft National Care Standards (2015); PANEL principles (2009); Equality Act (2010).

### 1. Standards of Care for Dementia in Scotland, Scotland's National Dementia Strategy (2011):<sup>9</sup>

As a person with dementia:

- I have the right to a diagnosis
- I have the right to be regarded as a unique individual and to be treated with dignity and respect
- I have the right to access a range of treatment, care and supports
- I have the right to be as independent as possible and be included in my community
- I have the right to have carers who are well supported and educated about dementia
- I have the right to end of life care that respects my wishes.

### 2. The Draft National Care Standards (October, 2015):<sup>10</sup>

- I am entitled to be respected
- I am entitled to compassion
- I am entitled to be included
- I am entitled to be treated fairly
- I am entitled to a responsive service
- I am entitled to be safe
- I am entitled to personal wellbeing.

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<sup>9</sup> Scottish Government. *Standards of Care for Dementia in Scotland, Scotland's National Dementia Strategy*. Edinburgh; 2011

[www.gov.scot/resource/doc/350188/0117212.pdf](http://www.gov.scot/resource/doc/350188/0117212.pdf)

<sup>10</sup> Care Inspectorate. National Care Standards – Draft for consultation (October, 2015)

These standards aim to ensure everyone in Scotland receives the same high quality of care.

3. The PANEL principles: developed by the United Nations and recommended by the Scottish Human Rights Commission.<sup>11</sup> The PANEL principles are fundamental to a human rights approach in practice, ensuring:

- Participation
- Accountability
- Non-discrimination and equality
- Empowerment
- Legality.

4. The Equality Act 2010:<sup>12</sup>

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. The public sector duties in relation to the Equality Act require public authorities to:

- eliminate unlawful discrimination, harassment, victimisation and other conduct prohibited by the Act
- advance equality of opportunity between people who share a protected characteristic and those who do not
- foster good relations between people who share a protected characteristic and those who do not
- aim to remove or minimise disadvantage experienced by communities who share a relevant protected characteristic
- gather evidence to enable policy-makers to understand the potential effects of decisions on different people covered by the duty; evidence on barriers to awareness of and access to services.

## 1.2 Recommendations

Recommendations from the National Advisory Group on Dementia and Equality consist of four key themes, listed below; specific recommendations for the five particular population groups are listed within each section.

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<sup>11</sup> United Nations. [www.alzscot.org/assets/0001/2458/UNCRPD.pdf](http://www.alzscot.org/assets/0001/2458/UNCRPD.pdf)

<sup>12</sup> Scottish Government. *The Equality Act 2010*.  
[www.gov.uk/guidance/equality-act-2010](http://www.gov.uk/guidance/equality-act-2010)

## 1.2.1 Key themes

### 1. Continue to raise awareness

Raising awareness and increasing understanding of signs and symptoms of dementia among all of Scotland's different population groups is fundamental to promoting early diagnosis. Further research and development work is needed within local communities of different population groups to develop culturally sensitive information about dementia and available services and to establish the most effective ways of raising awareness of dementia. This includes using appropriate terms, recognising that the word dementia does not translate into all languages or that it may not have meaning to a person with a learning disability.

Community connections, and the support of family and friends, need to be targeted as a key resource for both tackling stigma and encouraging early diagnosis and increasing quality of life within the community post diagnosis. Work undertaken in Scotland within different communities identified the importance of building up relationships and trust between the health and social care workforce, community workers and communities in order for discussion about dementia and the needs of the community to be met. We need to continue to recruit and build a workforce that is representative of the communities of Scotland.

### 2. Ensure robust services and support pathways

There is a need to continue to ensure clearly signposted, robust, culturally competent, locally informed services and post-diagnostic support pathways for people from the protected characteristic groups with a diagnosis of dementia, their carers and their families. This is vital with respect to the new agenda of health and social care integration and key to a whole system's approach.

### 3. Ensure appropriate knowledge and skills

Essential to encouraging early help-seeking among different population groups with protected characteristics, and to providing a supportive post-diagnostic pathway, is the need for an individualised care approach that recognises all aspects of an individual's identity, such as age, disability, race, religion and sexual/gender identity.<sup>13</sup> NHS Education for Scotland (NES) and the Scottish Social Services Council's (SSSC) 'Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers'<sup>14</sup> outlines the knowledge and skills, behaviours and attitudes the workforce needs in order to

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<sup>13</sup> White J. *Dementia and Equality briefing paper*. NHS Health Scotland: Edinburgh; 2015.

<sup>14</sup> NES and SSSC Promoting Excellence Framework.  
[www.gov.scot/resource/doc/350174/0117211.pdf](http://www.gov.scot/resource/doc/350174/0117211.pdf)

provide this type of service, linked to quality of life outcome indicators and stages of the dementia journey.<sup>15</sup>

The Promoting Excellence work programme will continue to develop as the evidence base for equality issues and dementia evolves. The aim is to ensure that the health and social care workforce in Scotland remains equipped with the knowledge and skills to deliver an individualised, culturally competent<sup>16</sup> care approach.

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<sup>15</sup> NES and SSSC Promoting Excellence Framework is mapped to the National Standards of Care for Dementia in Scotland. Educational resources also attend to the diverse needs of different people and communities and some foundational resources, for example 'Dementia Skilled – Improving Practice', particularly attends to equality and diversity issues.

<sup>16</sup> Scottish Executive, 'Fair for All: Working Together Towards Culturally Competent Services' NHS HDL (2002) 51

## 4. Research

Further research is needed:

- to determine the most effective ways to raise understanding about/ awareness of dementia among different population groups
- to identify and evaluate the impact of culturally competent dementia friendly community approaches in increasing awareness of dementia and diagnosis rates
- to collect Scottish incidence and prevalence data in relation to people with protected characteristics and dementia, including homeless people and those within the prison population.<sup>17</sup>

Below is a brief overview of the socio-economic perspective and that of gender, followed in more detail by the key themes and challenges with respect to the different population groups outlined above.

Throughout, it is important to be aware of the potential for compounded discrimination when someone has a range of characteristics which create barriers. Although the sections below are focused under separate headings it is clear that people may be potentially subject to multiple discriminations.

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<sup>17</sup> Scottish Government. *Scotland's National Dementia Strategy Equalities Impact Assessment*. Edinburgh; 2015.

## 2.0 Socio-economic inequalities

### 2.1 Brief overview

There are few large scale studies in the UK that have looked at social inequalities in dementia.<sup>18</sup> In a meta-analysis of eleven community-based cohort studies, it was observed that an association exists between lower occupational social class and dementia death in men, but not in women, after adjustment for alcohol consumption, smoking, cardiovascular disease, diabetes, psychological distress and age of leaving full-time education.

Given that it is known that health inequalities persist into old age and that many of the risk factors for dementia (including age, genetics, education and occupation, head injury, obesity, smoking, alcohol misuse, physical inactivity, hypertension, diabetes, high cholesterol, atrial fibrillation, anxiety, depression, social isolation) are associated with socio-economic disparities in mortality and morbidity, it is possible that, as the age structure of the population changes, social patterning in dementia may become apparent.<sup>19</sup> An association between deprivation and lower prescribing of drugs for dementia has been demonstrated in the UK, but interestingly not in Scotland.<sup>20</sup>

### 2.2 Recommendations

- Ensure a personal outcomes approach<sup>21</sup> is followed at the time of diagnosis to support the person with dementia and their family. This includes signposting to other services for example financial and benefit advice, employment, housing and access to services where the person lives, including rural and remote areas of Scotland, if these are of concern.

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<sup>18</sup> White J. *Dementia and Equality briefing paper*. NHS Health Scotland – citing Russ *et al* 2013.

<sup>19</sup> White J. *Dementia and Equality briefing paper*. NHS Health Scotland – citing Stark *et al* 2013.

<sup>20</sup> Cooper, Claudia, et al. 'Observational cohort study: deprivation and access to anti-dementia drugs in the UK.' *Age and Ageing*. 2015; afv154.

<sup>21</sup> [www.jitscotland.org.uk/action-areas/personal-outcomes/](http://www.jitscotland.org.uk/action-areas/personal-outcomes/)

## 3.0 Gender

### 3.1 Brief overview

Estimates of prevalence suggest that women are at increased risk of dementia. Of the estimated 800,000 people with dementia in the UK, two thirds are women, three quarters of family carers for people with dementia are women, and it is mostly women who deliver paid care.<sup>22</sup>

#### Age

65–69 years: men – 0.6%; women – 0.8%;

80–84 years: men – 5.2%; women – 7.2%;

85–89 years: men – 7.6%; women – 11.9%;

90 years + prevalence: men – 10.2%; women – 17.8%.<sup>23</sup>

**NB** Prevalence rates differ among people with learning disabilities particularly people with Down's syndrome, see section '6.0 Learning disabilities'.

The increased prevalence may reflect the longer life expectancy of women.<sup>24</sup> However, the age at which the current cohort of older women left full-time education may also contribute. The meta-analysis found an association between the age that women left full-time education and age of dementia death. This association remained after adjustment for alcohol consumption, smoking, cardiovascular disease, diabetes, psychological distress and occupational class. A similar association was not seen for men.<sup>25</sup>

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<sup>22</sup> Ludwin K. *Women and Dementia: All But Forgotten?* A literature review. 2015. [www.dementiawomen.org.uk/opus52/Women\\_and\\_Dementia\\_All\\_But\\_Forgotten\\_review\\_paper.pdf](http://www.dementiawomen.org.uk/opus52/Women_and_Dementia_All_But_Forgotten_review_paper.pdf)

<sup>23</sup> White J. *Dementia and Equality briefing paper*. NHS Health Scotland – citing Harding O *et al* 2013

<sup>24</sup> White J. *Dementia and Equality briefing paper*. NHS Health Scotland – citing Moriarty J *et al* 2011

<sup>25</sup> White J. *Dementia and Equality briefing paper*. NHS Health Scotland – citing Russ *et al* 2013

## 4.0 Younger onset dementia

### 4.1 Overview

The majority of people with dementia in Scotland are over 65 years of age. However, there are an estimated 3200 people who have younger onset dementia.<sup>26</sup> While many of the needs of younger people with dementia are similar to those of older people with dementia, there are some important differences, and there are many additional barriers to accessing support.

There has long been recognition of the need to improve the equity and range of service provision across the UK for people with dementia who are under the age of 65.<sup>27 28</sup> It has been highlighted that people who develop dementia before the age of 65 have usually occupied a precarious position with regard to receipt of services: 'The management and care of younger people with dementia tends to be uncoordinated and variable throughout the UK ... Several specialties play a part, sometimes reluctantly, but no single specialty has taken a lead to establish a coordinated policy for the development of services.'<sup>29</sup> It has also been recognised that '... despite the passing of time ... many issues have remained unresolved not only for service users and carers, but also service provision.'<sup>30</sup>

Many younger people with dementia are still in employment at the time of diagnosis, and while it is possible for people to continue employment post diagnosis, little is known about the supports required to successfully continue working.<sup>31</sup>

Challenges for people with younger onset dementia and their families fall into two main areas: diagnosis and post-diagnostic support; and the impact of the diagnosis on the person and the family.

- **Diagnosis and post-diagnostic support:** There are a number of barriers to people being diagnosed. Symptoms may be misattributed to other conditions such as stress, depression, menopause, excess alcohol use and relationship difficulties. Younger people are more likely than older people to have one of

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<sup>26</sup> Alzheimer Scotland, 2013, *Statistics: Number of people with dementia in Scotland 2013*. [www.st-andrews.ac.uk/media/human-resources/equality-and-diversity/carers/Statistics%20Dementia%20Scotland%202013.pdf](http://www.st-andrews.ac.uk/media/human-resources/equality-and-diversity/carers/Statistics%20Dementia%20Scotland%202013.pdf)

<sup>27</sup> Sperlinger D *et al.* *International Journal of Geriatric Psychiatry*, Vol. 9: 47–50. 1994

<sup>28</sup> Williams T *et al.* *Psychiatric Bulletin*, 25, 384–387. 2001

<sup>29</sup> Royal College of Psychiatrists, 2006, *Services for Younger People with Alzheimer's Disease and Other Dementias*. Royal College of Psychiatrists

<sup>30</sup> Roach, Keady *et al* 2012, 'It's easier just to separate them': practice constructions in the mental health care and support of younger people with dementia and their families. *Journal of Psychiatric and Mental Health Nursing*, 2012, 19, 555–562

<sup>31</sup> Ritchie L, Banks P, Danson M, Tolson D, and Borrowman F. (2015) Dementia in the Workplace: a review. *Journal of Public Mental Health*, 14(1) 24–34

the rarer causes of dementia where the symptoms are less familiar to clinicians.

- The initial pathway through diagnosis varies considerably for those aged under 65. Younger adults may be diagnosed either by psychiatrists based in older adult teams, psychiatrists based in mental health teams or through neurology departments in the acute sector. One consequence of this is that post-diagnostic support is not provided consistently within Health Board areas. Individuals may not receive post-diagnostic support depending upon location and which specialty makes the diagnosis. In short, there is currently no clear, agreed pathway for younger people with dementia, in terms of assessment and diagnosis, and post-diagnosis support.
- **Impact on individual and family:** Research has identified the particular subjective experience of younger people with dementia and their age-specific need for emotional support and psychological intervention.<sup>32</sup>
- Some of the issues highlighted by this research were, being ‘out of sync’ with social expectation of life stages,<sup>33</sup> premature retirement with implications for financial position; impact on family role and dynamics; a greater sense of social isolation and having a negative impact on self-identity and self-esteem. Families of younger people with dementia also have their own specific needs. It has been highlighted that particular family experiences differ from those caring for an older person with dementia, including for example: longer periods of uncertainty of diagnosis; dual loss of employment and income due to caring; dealing with feelings of frustration and grief; lack of peer support, and responsibility for families and young children.<sup>34</sup>

People with learning disabilities have a higher risk of developing dementia compared to the rest of the general population with a significantly increased risk, and at a much earlier age, for people with Down’s syndrome. For more on this see below section ‘6.0 Learning disabilities’.

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<sup>32</sup> Whiting S *et al.* ‘Voices of younger people with dementia’. PSIGE Newsletter, 81, 47–50. 2002

<sup>33</sup> Hendry LB, and Kloep M. *Lifespan development, resources, challenges and risks*. Cengage Learning EMEA. London: Thompson; 2002.

<sup>34</sup> Roach P *et al.* (2008). ‘Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice.’ *Reviews in Clinical Gerontology* 18(2): 165-172. Harris, P. B. (2004). ‘The perspective of younger people with dementia: still an overlooked population.’ *Social Work in Mental Health* 2(4): 17–36.

## 4.2 Key points

- Diagnosis usually takes longer to establish than in people with later onset dementia.
- Misdiagnosis is more common in people with younger onset dementia.
- Diagnostic and care pathways for younger people unclear, inconsistent and vary across and within Health Board areas.
- There are fewer age appropriate services and other forms of support, particularly respite and long stay care.
- Transitions to over 65 years services and long stay care are often unclear and can be complex.
- Negative financial impact can be significant where there is loss of employment, both for the individual diagnosed and their family members. This includes the difference in social service and welfare entitlements for working-age people, for example, free personal care is not available to people under 65. Pension arrangements can be affected, particularly if the person has left work before a diagnosis is made but when symptoms have developed to the extent that remaining in employment was too difficult, or was not sufficiently supported.
- Rarer forms of dementia are more common in this age group and require the health and social care workforce to have specialist knowledge to be able to provide appropriate care, advice and support.
- Impact on family relationships psychologically and emotionally can be greater.

The knowledge and experience of the National Advisory Group on Dementia and Equality with particular experience and practice working with people with younger onset dementia and the wider engagement with younger people with dementia agreed with the evidence found above. In Scotland there are examples of practice exploring ways to address some of these barriers. Examples highlighted by the Advisory Group are included in the recommendations.

## 4.3 Recommendations

**Increasing understanding • services and pathways • knowledge and skills • community • research**

- Increase understanding with public and health and social care workforce around younger onset dementia issues including rarer forms of dementia.

- Increase awareness of one-year post diagnostic guarantee and pathways among clinicians in acute sector, primary care and in adult mental health teams.
- Inform employers about dementia and how to support those with a diagnosis in the workplace recognising that changing the retirement age will increase the potential for an employee to receive a diagnosis while of employment age.<sup>35</sup>
- Provide clear information regarding pathways to diagnosis that is culturally sensitive and aware of sensory impairment.
- Improve communication of diagnosis to individual and family taking into account the impact of the diagnosis.
- Ensure each Health Board establishes and publishes clear diagnostic and post-diagnostic referral and care pathways.
- Ensure post-diagnostic support is age appropriate and offers information specific to this group taking account cultural and individual preferences.
- Increase access to appropriate counselling and psychological interventions.
- Develop services that are age appropriate including respite services, care at home and long stay care, to support individuals to continue to be active in communities and remain in their own home or in a supported living setting of their choice.
- Increase recognition among, and support for, the prison workforce for the rising number of people with dementia, of all ages, within prison populations; research further the prevalence and impact of dementia in this group.
- **Highlight and disseminate good practice, for example:**
  - Dementia Engagement and Empowerment Project (DEEP [www.dementiavoices.org.uk](http://www.dementiavoices.org.uk))
    - Equal Partners in Care (EPIC). [www.sssc.uk.com/workforce-development/our-current-work/epic-carers-and-young-carers](http://www.sssc.uk.com/workforce-development/our-current-work/epic-carers-and-young-carers)
  - – [NHS Health Scotland & Alzheimer Scotland Resource for people with younger onset dementia](http://www.healthscotland.com/uploads/documents/22313-Younger%20onset%20Dementia.pdf)
  - [www.healthscotland.com/topics/stages/healthyageing/dementia/younger-people-with-dementia.aspx](http://www.healthscotland.com/topics/stages/healthyageing/dementia/younger-people-with-dementia.aspx)

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<sup>35</sup> Recommendations outlined by the Dementia Engagement and Empowerment Project (DEEP) [www.dementiavoices.org.uk](http://www.dementiavoices.org.uk)

## 4.4 Focus group experiences and case studies

'Waiting eight months to find out what was wrong with [my husband] felt like a very long time. I had frequently asked the medics conducting the tests to tell us who would be collating the information and who would give us a diagnosis but no one was able to tell us this. We had not expected to be told by an eye specialist that [my husband] had Alzheimer's.'

'Twice [the GP told him] "it's just your age" and sent him home.'

'A colleague of [my husband] asked me if he was perhaps stressed as there were some concerns about his performance at work.'

'It soon became apparent that there were no local activities aimed at people with younger onset Alzheimer's.'

'Even though I am willing to be his one-to-one support we struggle to find indoor activities or events within our local community which are accessible.'

### Positive comments on what helped:

'From the first session we knew how valuable these workshops were. We were also with partners [and] carers ... so much help, advice and support.'

'The role of the link worker support is invaluable, we would not be where we are now without this essential support and we are extremely grateful that she is an important part of our ever evolving lives.'

## 5.0 Race and ethnicity

### 5.1 Overview

About 4% of the population in Scotland identify themselves as being from black and minority ethnic (BME) communities.<sup>36</sup> The majority of people from BME communities are from Asian (2.66%) or African-Caribbean (0.56%) backgrounds.<sup>37</sup> The proportion of BME people aged over 65 years at the Census 2011 was significantly less than the Scottish population in general. This pattern will continue to shift.

The estimated prevalence rates for dementia in the BME community are similar to the general population with the exception of younger onset (under 65 years). People of a younger age group from the BME community may be at higher risk of vascular dementia as this population may have higher risk factors for coronary heart disease.<sup>38</sup> However, people from the BME community who experience dementia are less likely to present to services and tend to make contact at a later stage of the illness.<sup>39</sup>

Evidence from systematic reviews of qualitative research suggests that barriers to help/support-seeking for dementia are knowledge, society and/or healthcare related.

- Knowledge related: a systematic review examined the determinants of whether and at what point people from BME communities present to services. It was found that beliefs about dementia and its causes acted as a barrier to seeking help. Overall, dementia was not seen as an illness for which help could or should be sought. Many believed that cognitive decline was just a 'normal' part of the ageing process. Linked to this belief was a perception that nothing could be done even if dementia was diagnosed.
- Society related: perceptions of stigma associated with a diagnosis of dementia were identified as a barrier to seeking help. With cultural expectations that relatives, particularly women, should care for the older person with dementia, seeking help may be frowned upon by other community members.
- Healthcare related: the GP is usually first point of contact for people with dementia and their families. Even though members of the BME community access primary care in a similar way to the general population, there is a

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<sup>36</sup> White J. *Dementia and Equality briefing paper*. Edinburgh: NHS Health Scotland; 2015 – citing Scottish Government, Summary: Ethnic Group Demographics, [www.scotland.gov.uk/topics/people/equality/equalities/datagrid/ethnicity/EthPopMig](http://www.scotland.gov.uk/topics/people/equality/equalities/datagrid/ethnicity/EthPopMig)

<sup>37</sup> White J. *Dementia and Equality briefing paper*. Edinburgh: NHS Health Scotland; 2015 – citing Scotland Census 2011.

<sup>38</sup> White J. *Dementia and Equality briefing paper*. Edinburgh: NHS Health Scotland; 2015 – citing Moriarty J *et al* 2011.

<sup>39</sup> White J. *Dementia and Equality briefing paper*. Edinburgh: NHS Health Scotland; 2015 – citing Mukadam N *et al* 2011.

reluctance to engage with mental health services. Previous experiences of discrimination may be a factor.<sup>40</sup>

Language barriers may contribute to misunderstandings about the healthcare system; older people from BME communities may have limited fluency and/or literacy in English. Indeed, some people may not be literate in their first language. Many of the assessment instruments used to diagnose dementia rely on literacy and/or English and may be culturally biased.<sup>41</sup>

There is very little information about interventions that aim to encourage help-seeking or raise awareness of dementia among the BME community. Practice examples suggest that targeted information that addresses the concerns of the BME community about dementia delivered by a trusted source, such as a community or religious organisation, might have greatest impact. However, while similar strategies have been found to improve attitudes to help-seeking for mental health issues, the numbers seeking help did not appear to change. It is likely that different approaches may work better in different communities in different places.

In the published literature, little or no mention was made of minority ethnic groups, such as Irish or gypsy/traveller communities. Research in Scotland highlights that gypsy/traveller communities report having 'experience of prejudice and fear of discrimination'. The fear of discrimination has an impact on help-seeking from services, as well as general awareness of existing services.<sup>42</sup> The gypsy/traveller community in consultation describe the challenges of access to sympathetic health and social services practitioners especially when they cross local authority and Health Board boundaries.<sup>43</sup>

## 5.2 Key points

- Strong cultural preference to deal with issues within the family.
- Stigma associated with illness and mental illness high.
- Language difficulties are a barrier to knowledge and to understanding the support available.

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<sup>40</sup> White J. *Dementia and Equality briefing paper*. Edinburgh: NHS Health Scotland; 2015

<sup>41</sup> White J. *Dementia and Equality briefing paper*. Edinburgh: NHS Health Scotland; 2015 – citing Moriarty J *et al* 2011; Khan F *et al* 2014.

<sup>42</sup> MECOPP. *Hidden Carers Unheard Voices Informal caring within Gypsy/traveller community in Scotland*. MECOPP; 2011-12

<sup>43</sup> Prior. February 2013, Support and care for people living with dementia from minority communities, North East Dementia Alliance citing Scottish Parliament Equal Opportunities Committee (2012) 3 Report (session 4) Gypsy/Travellers and Care

- Mixed and often limited levels of knowledge of dementia within cultures.
- Limited knowledge of available support.
- Distrust of services through experience of inadequate health and social care workforce knowledge and sensitivity around cultural awareness.

The members of the National Advisory Group on Dementia and Equality with particular experience and practice working within different race and ethnic communities agreed with the 'Dementia and Equality' evidence briefing paper findings. Further focus group work in Scotland in 2015 also reflected the evidence found above. In Scotland there are examples of practice exploring ways to address some of these barriers within different communities. Examples highlighted by the Advisory Group are included in the recommendations.

### 5.3 Recommendations

#### **Increasing understanding • services and pathways • knowledge and skills • community • research**

- Provide, for people with a diagnosis of dementia, an individualised care approach that recognises all aspects of a person's identity, such as race, religion and sexual identity. This is essential for encouraging early help-seeking among different population groups.
- Build close relationships and trust with different communities – recommend community workers, trained in dementia, to build up relationships and explore and develop appropriate ways of raising awareness of dementia.
- Provide services for people with a diagnosis of dementia and their families that are culturally competent. A culturally competent service is defined as 'a service which recognises and meets the diverse needs of people of different cultural backgrounds ... It includes, but is not limited to, making provision for religious and cultural beliefs such as worship, diet and hygiene requirements, catering for communication and language diversity'.<sup>44</sup>
- Facilitate understanding of different communities by having staff members from diverse population groups, as well as good relations with a reference group.
- Provide health and social service workforce with relevant and timely learning and development in order for people to feel confident and competent to deal with language and cultural differences.

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<sup>44</sup> White J. Dementia and Equality, briefing paper. Edinburgh: NHS Health Scotland; 2015 – citing MECOPP, Creating an alternative future. Edinburgh: MECOPP.

- Use assessment instruments that are culturally sensitive and do not rely on literacy and/or fluency in English or are culturally biased.
- Work with local communities of different population groups to develop and distribute culturally sensitive information about dementia and available services.
- Research the most effective ways to raise awareness of dementia among different population groups.
- **Highlight and disseminate good practice, for example:**
  - Alzheimer Scotland’s project in North Lanarkshire, MECOPP in Edinburgh and Older People Services Development Project in partnership with Trust, Hanover and Bield.<sup>45</sup>

## 5.4 Focus group experiences and case studies

‘The [Muslim] community is not aware that this is an illness.’

‘Dementia is part of ... ageing, “is part of growing old” and the word dementia [does] not exist in [our] language.’

‘Even the people who know, they will never use the word dementia.’

‘It is very hard to accept help and support because of our culture, caring for relatives is our responsibility.’

‘About one and a half year after diagnosis we read an article in Polish Magazine in Scotland about Polish worker in Alzheimer Scotland, based in Motherwell, we contacted her and everything changed.’

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<sup>45</sup> Trust, Hanover, Bield. Dementia Consultation Report Older People Services Development Project (2012)  
[www.equalityscotland.com/assets/pdf\\_docs/Dementia/Consultation\\_Report\\_-\\_Final\\_July\\_2013.pdf](http://www.equalityscotland.com/assets/pdf_docs/Dementia/Consultation_Report_-_Final_July_2013.pdf)

'Muslim community do not use the services because of their culture, language barriers and lack of understanding of their needs.'

'Support is needed because people [like] us need someone who understands the language and our culture.'

'There is a need for bilingual workers as more and more Polish people will use services.'

'Now Mum has social worker and services in place but it is more than two years after diagnosis.'

'We are surprised that there are people – who care for Mum and our family and I – ready to help.'

'If someone in the family has medical background they know better and is possible that the family will look for the diagnosis.'

'The stigma connected to dementia has nothing to do with Islam religion, it is more about family culture, lack of education and rural background, and this might be passed on to the next generation.'

## 6.0 Learning disabilities

### 6.1 Overview

People with learning disabilities have a higher risk of developing dementia compared to the rest of the general population, with a significantly increased risk for people with Down's syndrome at a much earlier age. It is predicted that 1 in 3 people with Down's syndrome over the age of 50 will develop dementia. Life expectancy of people with Down's syndrome has increased significantly and the incidence and prevalence of Down's syndrome is not decreasing. Pre-existing cognitive impairment, and poor short term memory for some, makes diagnosis difficult; symptoms affecting personality, emotion or behaviour may manifest before any change in language ability or memory.<sup>46</sup> The onset of dementia for people with learning disabilities may be more difficult to detect given the complexity of co-morbidity and a lack of a clear baseline against which to measure decline.

Communication difficulties, and an increased potential for sensory impairment, also hinder diagnosis as the person with learning disabilities may be unable to articulate what is happening to them (refer to section on Disabilities – Sensory impairment 8.0).

There is also a high risk of misdiagnosis – the common differential diagnoses for individuals with Down's syndrome presenting with loss of skills are depressive illness, sensory impairments (hearing and/or visual), hypothyroidism, early menopause, pain, obstructive sleep apnoea and dementia. The reason for a change in behaviour or functioning may not be associated with dementia; people with a learning disability are susceptible to age-related health conditions that should always be investigated and treated as part of the assessment process.<sup>47</sup>

Not all health and social care workers or families will be knowledgeable about dementia in people with learning disability so may miss signs and symptoms of early stages of dementia. Provision of post-diagnostic support is less clear; there may be a lack of crossover care between older people's services and learning disability services; the latter being the best positioned to coordinate care.

Health and social care workers and family carers need to ensure that people with learning disabilities and dementia receive a consistent approach to care. Therefore people with learning disabilities, their families and carers need to be given the opportunity to understand from an early stage the nature of the illness, how it may develop over time, what support will be available and from whom. Timely diagnosis, skilled and knowledgeable workers, both generally trained and specialist staff, and a

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<sup>46</sup> White J. *Dementia and Equality, briefing paper*. Edinburgh: NHS Health Scotland; 2015 – citing Sheehan *et al* 2014.

<sup>47</sup> British Psychological Society. *Dementia and People with Intellectual Disabilities*. Leicester: BPS; 2015

clear post-diagnostic pathway will lead to a more supportive environment and reduce distress.

## 6.2 Key points

- People with learning disabilities and particularly Down's syndrome are at high risk of younger onset dementia.
- Onset of dementia may be more difficult to detect, particularly where there is no baseline information from which a decline in functioning can be measured.
- Workforce development and learning is essential as health and social care workers may know less about dementia associated with learning disability and vice versa.
- Misdiagnosis is common; not everyone with Down's syndrome will develop dementia although typically frontal lobe changes will be experienced from an early age.
- Most areas in Scotland do not yet have a post-diagnostic pathway in place for people with a learning disability after a diagnosis of dementia.
- The role of friends, in addition to family and the health and social care workforce, is often under recognised when supporting people with learning disabilities and dementia to live well.

The members of the National Advisory Group on Dementia and Equality with particular experience working with people with learning disabilities and their families added to the Dementia and Equality evidence briefing paper findings, with further practice-based recommendations. Focus group work in Scotland, 2015, also reflected the evidence found above.

## 6.3 Recommendations

### **Increasing understanding • services and pathways • knowledge and skills • community • research**

- Increase knowledge and understanding of potential younger onset of dementia in people with learning disabilities, among families, carers and friends.
- Increase accessibility of information about dementia in appropriate formats recognising that this may be non-verbal; ensure follow up information is available to give people with a learning disability every chance of understanding the diagnosis, how dementia may affect them and what support is available.

- Establish a baseline assessment of functioning against which to compare future suspected changes. This should begin at age 30 with adults who have Down's syndrome.
- Screen adults with Down's syndrome over the age of 40 every two years and annually after the age of 50. This is recommended by the British Psychological Society because of the increased risk of dementia and the prevalence of undetected but treatable illnesses. This should link to the person's overall health action plan.<sup>48</sup>
- Recommend, for individuals with a learning disability other than Down's syndrome, a baseline assessment at age 50 with no further action or screening until concerns are raised.
- Ensure access to appropriate assessment tools for example the 'National Task Group Early Detection Screen for Dementia' (NTG-EDSD) that can be used for the early detection of dementia, or other treatable conditions, in adults with learning disability. A Scottish version has recently been published which complies with the Scottish Dementia Strategy 2013-16.<sup>49</sup>
- Ensure a multidisciplinary approach is taken to diagnosis, with care coordinated from learning disability services.
- Include a Vision Support Officer (complex needs) in the multidisciplinary team as adults with learning disabilities are ten times more likely to have sight impairment than the general population.<sup>50</sup>
- Ensure that all workforce involved in the care and support of people with Down's syndrome and dementia have access to relevant development and learning in both learning disability and dementia. This includes day services, community supports and social care workers.
- Incorporate sight loss into learning disabilities and dementia training. This will ensure that visual behaviours which indicate sight loss are not attributed to dementia.
- Ensure training is not a 'one-off' activity, and that learning is delivered on an ongoing basis as the person's dementia progresses so that staff are capable of meeting changing needs and achieving the best outcomes for the person.

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<sup>48</sup> British Psychological Society. *Dementia and People with Intellectual Disabilities*. Leicester: BPS; 2015

<sup>49</sup> National Task Group on Intellectual Disabilities and Dementia Practices, USA. Adapted in Scotland by Dr Karen Watchman, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland; Nicola Ewing, Edinburgh City Council and Susan Scotland, NHS Lothian.

<http://aadmd.org/sites/default/files/NTG-EDSD-Final-Scotland%20%281%29.pdf>

<sup>50</sup> Emerson, Robertson, J. *Maggie Woodhouse Research*, University of Cardiff; 2011

- Ensure continuity of health and social care workers if possible for people with a learning disability who are already accessing services.
- Ensure the post-diagnosis support plan is clear, person-centred, relationship focused, consistently applied and provided for longer than one year.
- Review on a regular basis the support given to people with learning disabilities and dementia. This includes ensuring any information is in an appropriate or pictorial format, and reviewing the level of social care support required including night-time care.
- Prioritise accommodation planning that covers different models of care to ensure increased support is available, whether in the persons' own home, shared accommodation or with family.
- Ensure continuity, where possible, of living in an environment that is familiar to the person. A move to a generic care home for older people should not be viewed as a first or obvious choice for an individual with a learning disability.
- Adopt, for each area, a Learning Disability and Dementia Action Plan<sup>51</sup> and integrated care pathway incorporating end of life care planning to support the provision of high quality assessment, intervention and care. This will offer guidance to families, particularly about who to take early concerns to, and will provide health and social care workers with support in implementing the Standards of Care for Dementia in Scotland.
- Conduct research to increase the evidence base as people age with a learning disability, especially people with Down's syndrome.<sup>52</sup>

## 6.4 Focus group experiences and case studies

'Others who attended the day service with her were becoming increasingly annoyed and frustrated in the changes in Susan's behaviour. Her parents were unaware that she was at risk of younger onset dementia and were reluctant to accept that there was anything wrong. Susan herself knew that something "wasn't right" although she didn't understand what it was.'

'Susan had not had a baseline assessment when she was younger which meant it was difficult to monitor changes as she got older.'

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<sup>51</sup> British Psychological Society, Dementia and People with Intellectual Disabilities. 2015

<sup>52</sup> British Psychological Society, Dementia and People with Intellectual Disabilities. 2015

'Jenny's Diary'<sup>53</sup> helped Susan understand that the changes she was experiencing weren't her fault. Senior staff attended a course in learning disability and dementia at the University of the West of Scotland. This took a cascade approach with the focus on supporting them to deliver training locally within their own organisation. Staff attending the course took away a range of training materials ... more importantly they took away confidence and new knowledge that enabled them to share learning with other staff. This led to a change in practice and a more strategic approach to supporting the residents but also their housemates and peers too.'

'Mrs A cares for her sister who has Down's syndrome and dementia. Mrs A's mother also had dementia and Mrs A has witnessed the difference in the level of care provided to her mother who received good care and her sister who is receiving no support and no help with future planning.'

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<sup>53</sup> Watchman K, Tuffrey-Wijne I, and Quinn S. Jenny's Diary: a resource to support conversations about dementia with people who have a learning disability. London: Alzheimer's Society; 2015 [www.uws.ac.uk/jennysdiary](http://www.uws.ac.uk/jennysdiary)

## 7.0 Lesbian, gay, bisexual and transgender (LGBT)

### 7.1 Overview: issues faced by older lesbian, gay and bisexual people

The size of Scotland's lesbian, gay and bisexual (LGB) population is not known as none of the Scotland-wide surveys (e.g. the 2011 Census or the Scottish Household Survey) asks for information about sexual orientation. However from UK research the size of the population is estimated at 5-7% of the adult population, thus representing a very significant minority.<sup>54</sup>

Older lesbian, gay and bisexual people are more likely to be single and live on their own than heterosexual people. They are less likely to have children or regularly see family members. This means that LGB people are less likely to have a partner or family to support them as they get older, and more likely to need social services for help.

Older LGB people have lived the majority of their lives in far less liberal times (e.g. male homosexuality was illegal in Scotland until 1980; a significant proportion of older LGB people may have been considered for or undergone treatment to 'cure' them). Also LGB older people in particular can be reluctant to disclose their LGB status having previously faced discrimination or had poor experiences of services and support because of their status.

Although public attitudes towards LGB people in Scotland have shifted, 27% of people in Scotland still hold discriminatory attitudes towards same sex relationships.<sup>55</sup> Both overt and subtle discrimination towards LGB people continues to exist. Societal attitudes thus continue to be a barrier to help-seeking for dementia.

#### 7.1.1 Key points

- Healthcare: many LGB people are not 'out' to their GP and may be reluctant to engage with dementia and mental health services because homosexuality was until relatively recently considered a mental disorder. This means many individuals delay or avoid presenting to medical services with early signs of dementia.
- Social services: many LGB people say they would be uncomfortable with care home staff or paid carers knowing their sexual orientation. Fear of facing discrimination, hostility and prejudice means some LGB people avoid seeking support from social services when they need them.

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<sup>54</sup> Are we being served? DVD, [www.lgbthealth.org.uk](http://www.lgbthealth.org.uk) (accessed December 2015)

<sup>55</sup> Public Attitude to Discrimination in Scotland, 2010; Scottish Government Social Research, 2011.

- Support groups: older LGB people may feel out of place in traditional dementia support groups and dementia cafes and may fear that others will react negatively if they talk openly about their partner or family of choice. They may therefore feel more comfortable in a group made up of other LGB people; but there may be few or no services of this kind available.<sup>56</sup>

## 7.2 Overview: issues faced by older transgender people

A transgender person is someone whose personal sense of gender does not correlate with his or her assigned gender at birth (gender dysphoria). Transgender is a broad term that includes all those who experience some degree of gender variance, which in most cases requires no medical intervention. The term includes transsexuals, who are transgender people whose strong feelings of gender dysphoria lead the individual to transition from male to female or vice versa. Transgender people constitute a ‘hidden population’, one that is both very diverse and very private. Many transgender people, including those who are living permanently in their acquired gender, may keep their transgender identity private and will not be visible as transgender.

The transgender population is relatively small and there are no reliable estimates. Available figures usually relate only to those people seeking gender reassignment treatment to ‘transition’, currently some 10,000 individuals in the UK, but numbers are growing relatively rapidly.

Many older transgender people have lived during a time when being transgender was considered a mental health disorder. They are more likely to be single, to live on their own, less likely to have children, or may have poor or fractured relationships with family members. If people do not have a partner or family to support them as they get older, they are more likely to need to use social services for help.

In Scotland 55% hold discriminatory attitudes towards transgender people.<sup>57</sup> For older transgender people in particular, discrimination is something that is likely to have affected many different facets of their lives such as employment and finances, social networks, personal and family relationships, and health.<sup>58</sup>

There is minimal literature specifically around transgender people and dementia. However widespread discrimination and poor experiences of healthcare<sup>59</sup> means that societal and healthcare attitudes are a very significant barrier to help-seeking for dementia.

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<sup>56</sup> Supporting lesbian, gay and bisexual people with dementia. Alzheimer’s Society; 2012.

<sup>57</sup> Public Attitude to Discrimination in Scotland: 2010, Scottish Government Social Research, 2011.

<sup>58</sup> Dementia, transgender and intersex people; do service providers really know what their needs are, Alzheimer’s Australia, 2014.

<sup>59</sup> Trans mental health study, Scottish Transgender Alliance, 2012.

A number of issues might be of particular concern to this population. Namely, seeking assistance with activities of daily living, including personal care, presents particular challenges. Also long term hormone therapy (testosterone or oestrogen) may be used as part of their transition to maintain physical changes and support emotional and psychological wellbeing. Cessation of hormones, which can happen due to the onset of dementia, admission to hospital or care home, can have a significant negative mental and physical impact.

### 7.2.1 Key points

- Healthcare: Transgender people's identity may well be hidden. They may be reluctant to engage with mental health services because being transgender was until relatively recently considered a mental disorder.
- Social services: seeking assistance with activities of daily living, including personal care, presents particular challenges. Interruption of long term hormone therapy can have a significant negative mental and physical impact.
- Support groups: older transgender people may feel out of place in traditional support groups.<sup>60</sup>

## 7.3 Overview: LGBT carers

There is evidence to suggest that LGBT people play an important and unique role in care giving, both as carers for family of origin and 'family of choice'. A family of choice is a series of supportive relationships that can be likened to that of biological family. Care for members of a family of choice is especially important in the case where there is no other support network and no appropriate services available or accessible. Also unlike the general population, where women are the major care providers, within the LGBT community men are just as likely to provide informal care.<sup>61</sup>

The lack of appropriate support for LGBT carers further contributes to stress of carers who may already be experiencing financial, physical and emotional pressures.

Also there are challenges within birth family dynamics where LGBT carers may be assumed to be single and asked to provide care to a family member who may not have been accepting of their sexual orientation or gender identity. An LGBT person who is caring for their partner with dementia may also face exclusion from decision making by their partner's biological family in relation to formal care and end-of-life arrangements.

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<sup>60</sup> Supporting lesbian, gay and bisexual people with dementia, Alzheimer's Society, 2012.

<sup>61</sup> Dementia, transgender and intersex people; do service providers really know what their needs are, Alzheimer's Australia, 2014.

LGBT carers can experience discrimination when accessing residential care, medical and other health and older people's care services including lack of recognition of their relationships, presumptions of heterosexuality, awkwardness or avoidance from staff in acknowledging relationships. Consequently people may be reluctant to access support services.

### **7.3.1 Key points**

- Care for members of a family of choice is especially important where there is no other support network and no appropriate services available or accessible.
- LGBT carers can experience discrimination when accessing residential care, medical and older people's care services, through lack of understanding of their relationships with the person with dementia.
- Lack of appropriate support further contributes to stress of carers who may already be experiencing financial, physical and emotional pressures.
- LGBT carers may face exclusion from decision making by their partner's biological family in relation to formal care and end-of-life arrangements.

## **7.4 Recommendations**

### **Increasing understanding • services and pathways • knowledge and skills community • research**

- Ensure workforce is informed and open: culturally appropriate care is about respecting and preserving the person's identity, who they are, their whole life history, service providers who have had little contact with LGBT people need to access specialist sources of support for a LGBT person with dementia or their carer.
- Incorporate personal care needs into care plans: the particular personal care needs of a transgender person should be included. Workforce development training, which challenges assumptions and increases cultural awareness of the needs of transgender people, may be required to ensure their personal care needs are met in a respectful way.
- Provide a safe space: concerns exist not just about the attitudes of the workforce but also attitudes of other service users with dementia. A clear zero-tolerance policy to homophobic, biphobic and transphobic language and behaviour should be adopted to ensure the emotional, and sometimes physical, safety of LGBT people.

- Include proactively: it is important that publicity material regarding dementia or/and policy documents are pro-actively inclusive of LGBT identities. Provide prominence to policies relating to confidentiality.

**Highlight and disseminate good practice, for example:**

- Information and training resources are available online to help organisations provide services that are inclusive and welcoming to LGBT people  
[www.lgbthealth.org.uk/services-support/lgbt-age/professional-resources/](http://www.lgbthealth.org.uk/services-support/lgbt-age/professional-resources/)
- The LGBT Age Audit Tool helps those providing support services to older people identify practical steps towards ensuring LGBT-inclusive practice  
[www.lgbthealth.org.uk/wp-content/uploads/2015/09/LGBT-Age-Audit-Tool-final.pdf](http://www.lgbthealth.org.uk/wp-content/uploads/2015/09/LGBT-Age-Audit-Tool-final.pdf)

## 7.5 Focus group experiences and case studies

‘We decided to be out. To all the service providers that came in we said we are a gay couple ok, and all of them said, “it’s ok we treat everyone the same” and so on, and we immediately said “that is not what we want”. We don’t want to be treated the same as everyone else but that gives you a common ground, we want to be treated as a gay couple.’

‘It has been such a fight and a journey. And I’m not prepared to put that back away again, for someone to take that away from me. And therefore, I want to maintain that through the rest of my life. I want a care system that will support me, because being gay is a significant part of me, it’s not the only part of me, but it is a significant part of me.’<sup>62</sup>

‘I have realistic concerns that I will not be treated as I would like when I am dependent on others, that people will attempt to force me into being the wrong gender.’<sup>63</sup>

‘With some people who are trans the dementia might cause them to regress to their birth gender and forget they have transitioned. Families can take

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<sup>62</sup> Over the Rainbow: LGBT people and dementia project, University of Worcester, 2015.

<sup>63</sup> Dementia, transgender and intersex people; do service providers really know what their needs are, Alzheimer’s Australia, 2014.

advantage of that ... keep all their trans support network away. Services need to take this into account and not collude with family or other people who are taking advantage of someone's situation, their dementia, to make them into a person that they did not want to be.'<sup>64</sup>

'Dementia, as a condition, is very isolating. It can be very isolating for the carers ... and I think possibly for LGBT people it is doubly isolating, in terms of not just wanting to talk to other carers, but other carers in your situation, lesbian carers rather than heterosexual ones, so I can talk freely, without judgements, without having to constantly explain.'<sup>65</sup>

'I am dependent on carers [staff] and I am frightened ... what if they find out that I am a lesbian ... what are they going to do to me ... I have de-gayed my house ... this is much worse than the 50s. I want to be able to be gay in my last days – I don't want to have to hide again and I particularly don't want to have to hide because the home help is coming round ...'<sup>66</sup>

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<sup>64</sup> Over the Rainbow: LGBT people and dementia project, University of Worcester, 2015.

<sup>65</sup> Over the Rainbow: LGBT people and dementia project, University of Worcester, 2015.

<sup>66</sup> The Dementia Challenge for LGB Communities: roundtable discussion, National LGBT Partnership, 2014.

## 8.0 Sensory impairment

### 8.1 Overview

- Almost 2 million people in UK are living with sight impairment
- 10 million people in UK are living with hearing impairment
- 1 in 5 people aged 75+ are living with sight impairment
- 1 in 2 people over the age of 90 is living with sight impairment
- 40% of people aged 50+ are living with hearing impairment
- 70% of people over the age of 70 are living with hearing impairment.<sup>67</sup>

We know that dementia is a leading cause of disability in older people and many people have physical co-morbidities, chronic conditions, such as sensory impairment that can impact further on their abilities.<sup>68</sup>

People with sensory impairment, who develop dementia face additional challenges, including an increased sense of disorientation and risk of social isolation. Those with sight loss may also suffer from disruptive visual hallucinations.<sup>69</sup> The onset of dementia may be more difficult to detect by family and carers. Equally it may be difficult for the person with sensory impairment to communicate what is going on for them.

Additionally, there is a national shortage of both interpreters for British Sign Language (BSL) and health and social care workers who can communicate in BSL. When workers don't understand BSL there is a danger that they won't be able to assess an individual and appreciate the differences between what is usual behaviour and unusual, symptomatic behaviour. This applies potentially to the whole care pathway.

On the other hand, there are people who may be living with a 'hidden and untreated' sensory impairment, including people with dementia. Hearing or sight problems may go unrecognised if behaviours, associated with sensory loss, are thought to be symptoms of other complex needs such as learning disability, dementia or stroke. People with complex needs may not be aware that they have a sensory problem and may not be able to tell others.

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<sup>67</sup> Edinburgh and Lothian's Joint Sensory Partnership 'Hidden Sensory Loss Sensory Champion training. [www.jointsensorypartnership.com](http://www.jointsensorypartnership.com).

<sup>68</sup> NHS Health Scotland, Dementia and Equality, briefing paper (White, J, 2015) citing Moriarty, J et al. 2011

<sup>69</sup> NHS Health Scotland, Dementia and Equality, briefing paper (White, J, 2015) citing DOH National Dementia Strategy 2011

Consequently, carers and health and social care workers may think the individual can see and hear perfectly well when this may not be the case. This 'hidden sensory loss' can have a serious impact on the quality of life of a person with complex needs. There can also be difficulties accessing dementia services – including diagnostic and post-diagnostic services because of the impairment.<sup>70</sup>

Having a person who is deaf being cared for and supported by health and social care workers who can't communicate for example using BSL is a deprivation of human rights and severely affects the wellbeing of the Deaf BSL user as well as creating anxiety with family and other informal carers.

## 8.2 Key points

- People with sensory impairment and dementia risk social isolation.
- Sensory impairment may be hidden – carers/family/health and social care workers may attribute behaviours connected with the impairment to learning disability or dementia.
- There is a national shortage of both BSL interpreters and health and social care workers who can communicate in BSL.
- Those with complex needs may be unable to tell others what they are experiencing.
- Accessing services may become too difficult to manage.
- Sensory impairment is a potential indicator of some forms of dementia.

The members of the National Advisory Group on Dementia and Equality with particular experience and practice working with the agenda of long term conditions and sensory impairment agreed with the Dementia and Equality evidence briefing paper findings. Further focus group work in Scotland in 2015 also reflected the evidence found above. In Scotland there are examples of practice exploring ways to address some of challenges posed by sensory impairment, these are included in the recommendations.

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<sup>70</sup> Edinburgh and Lothian's Joint Sensory Partnership: Hidden Sensory Loss Project pdf, 2013. . [www.jointsensorypartnership.com](http://www.jointsensorypartnership.com).

## 8.3 Recommendations

### **Increasing understanding • services and pathways • knowledge and skills • community • research**

- Increase access to sensory impairment learning for health and social care workforce.
- Increase understanding and knowledge of sensory impairment and its association with dementia.
- Require health and social care workforce to know there is a duty to provide information in accessible formats, such as using BSL, in order to remove or minimise disadvantage.
- Increase training for health and social care workers in BSL.
- Increase access to workers such as interpreters trained in BSL.
- Use assessment instruments that are culturally sensitive and appropriately geared for people who have sight or hearing impairment or loss, including Deaf BSL users.
- Increase health and social care workforce understanding of how best to support people with impairment or loss of sight or hearing and dementia. Health and social care workers should have understanding of visual perception difficulties and tailor support to address depth perception, visual acuity and reduced colour contrast sensitivity. Consideration should be given to workforce development and learning methods for example RNIB eLearning modules on sight loss and dementia, and 'Promoting Excellence' learning resources.
- Increase awareness of support services for clients with sensory loss including for example Deaf Action, or communications connection services such as Deaf Connections.<sup>71</sup>
- Consider the inclusion of a sensory passport which could accompany individuals on their journey through health and social care services.<sup>72</sup>
- Require more support with respect to wearing and use of hearing aids. Referral to further accessible technology may be required.
- Consider raising awareness of importance of sensory-sensitive public spaces in dementia-friendly community work. For example restaurants having a sensory-sensitive quiet room with no background music playing.

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<sup>71</sup> [www.deafconnections.co.uk](http://www.deafconnections.co.uk) [www.deafaction.org.uk](http://www.deafaction.org.uk)

<sup>72</sup> Edinburgh and Lothian's Joint Sensory Partnership 'Hidden Sensory Loss Sensory Champion training. [www.jointsensorypartnership.com](http://www.jointsensorypartnership.com)

- **Highlight and disseminate good practice, for example:**
  - College of Optometrists guidance for the profession in the Guidance for Professional Practice, which has a section 'Examining patients with dementia or other acquired cognitive impairment', which contains much valuable advice for practitioners (College of Optometrists 2014).
  - 'Dementia and sensory loss' component of The Social Care Institute for Excellence's Dementia Gateway ([www.scie.org.uk/publications/dementia/living-withdementia/sensory-loss/files/sight-loss.pdf](http://www.scie.org.uk/publications/dementia/living-withdementia/sensory-loss/files/sight-loss.pdf)). The sensory loss section of the Gateway covers hearing loss, deafness and dual sensory loss, in addition to sight loss.
  - VISION2020 has a dementia and sight loss group and umbrella organisation which produces practical factsheets
  - RNIB Best practice on falls prevention
  - Scottish Dementia Working Group on Sensory Loss and Dementia 2015 publication produced by Agnes Houston [www.sdwg.org.uk/wp-content/uploads/2008/05/Sensory-Leaflet.pdf](http://www.sdwg.org.uk/wp-content/uploads/2008/05/Sensory-Leaflet.pdf)
  - Edinburgh and Lothian's Joint Sensory Partnership [www.jointsensorypartnership.com](http://www.jointsensorypartnership.com)

## 8.4 Focus group experiences and case studies

'We waited eight months to find out what was wrong.... We had not expected to be told by an eye specialist that [my husband] had Alzheimer's'

'Sarah, a lady in her 50s, found herself in limbo after experiencing significant vision difficulties but being discharged from ophthalmology. She lives alone. With Sarah's consent the vision support officer now also works closely with professionals involved in her support. While working with the vision support officer, Sarah was also allocated her dementia link worker. This has meant that Sarah and her family now feel fully supported from both the vision and the dementia angle.'

## 9.0 Concluding remarks

It is intended that the recommendations outlined in this report, put forward by the National Advisory Group on Dementia and Equality, will inform the Scottish Government in the development of Scotland's Dementia Strategy going forward. Importantly, the recommendations in this report are for wider dissemination now as guidance, to encourage discussion and inform practice in providing culturally appropriate, timely diagnosis and post-diagnostic support to all of Scotland's population.

Sincere thanks go to the many contributors to the recommendations in this document: to the Advisory Group; to the wider health and social care workforce; and above all to those people with dementia, their families and carers, who have so generously shared their experiences of the illness, their challenges and needs, so that all lives touched by dementia can be lived and supported as fully as possible within dementia-enabled and dementia-friendly local communities in Scotland.

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# Appendix 1

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## Appendix 2

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