

Equality Impact Assessment Dementia Strategy 2017-2020, Version 1, October 2016

Section 1 – Introduction

The aim of the strategy is that people in South Gloucestershire with dementia and their carers are able to live well and are supported to do so throughout the progression of the disease. Through this strategy and accompanying action plan we will join up health and care support to put the individual at the centre of their support and empower them to remain independent and well. Making opportunities and activities equitable for all.

Our priorities for action:

1. Increase awareness and understanding of dementia amongst professionals and the public;
2. Improve diagnosis rates and ensure a timely diagnosis for those with dementia;
3. Ensure high quality information about dementia, local services and support for all with a dementia diagnosis and their carers;
4. Develop care and support to meet the needs of individuals with dementia and their families and other carers, to maintain independence and avoid crisis;
5. Recognise the contribution of carers, and encourage and enable them to look after their own health and wellbeing as well as those they care for;
6. Improve support for people who can no longer live at home, supporting care homes to meet the needs of people with dementia and developing alternatives;
7. High quality hospital care for people with dementia, including pathways to ensure appropriate and timely discharge;
8. High quality end of life care.

Section 2 – Research and Consultation

According to the Dementia UK 2014 report (Alzheimer's Society, 2014), the total age standardised prevalence of dementia amongst those aged 65+ in the UK is 7.1%, equal to 1 in 14 of those aged 65 and over. If this proportion is applied to the South Gloucestershire population this equates to nearly 3,450 people aged 65 or over that are estimated to have some degree of dementia. More recent estimates are that there were 3,282 people with dementia in South Gloucestershire in October 2015.

Age & Gender

The national breakdown of diagnosis by gender is 61% women and 39% are men. Women over 60 are twice as likely to develop Alzheimer's disease than breast cancer (Alzheimer's Research).

Although Dementia predominately affects older adults, it is known to affect younger adults. It is estimated that 4.1% of men with dementia and 1.6% of women with dementia in South Gloucestershire are under the age of 65: approximately 135 people. (JSNA 2016).

Young onset dementia prevalence (Meeting the needs and expectations of younger people with dementia, Alzheimer's Society, 2016)

Area	30-34	35-39	40-44	45-49	50-54	55-59	60-64	Total
NHS South Gloucestershire	1	1	3	6	11	21	134	177

Ethnicity

Due to lack of evidence, the dementia prevalence figures for people from a Black, Asian and Minority Ethnic (BAME) background in England and Wales have not been updated in the 2014 report (Alzheimer's Society 2104). However in 2011, there were 25,000 people with dementia from BAME groups in England and Wales (Alzheimer's Society, 2012). This number is expected to double to 50,000 by 2026 and rise to over 172,000 by 2051.

It is reported within BAME communities, fewer referrals from GP's reach a psychiatrist or neurologist. This can result in misdiagnosis, inappropriate treatment and ultimately a heavier burden on families and society to manage. One of the main reasons for lack of referrals from BAME groups is due to inadequate diagnostic assessments. The thinking and memory tests that are carried out in the GP clinic compare performance to the majority White British population norms. So, the lack of BAME norms on these tests is a huge hindrance in trying to reach a diagnosis of dementia in those people.

People with a learning disability and dementia

People with learning disabilities may have a higher risk of dementia because of premature ageing and, in the case of Down's Syndrome, genetic factors. As the population ages, additional specialist services will need to be provided to meet the needs of older people with learning disabilities and dementia. Projections suggest that, by 2030, the number of people aged over 70 using services for people with learning disabilities will more than double (British Institute of Learning Disabilities, 2012).

Section 3 – Identification & Analysis of Equalities Issues & Impacts

We regularly seek and receive feedback from carers, AWP and other stakeholders on South Glos Dementia Planning Group, Bristol & South Glos Dementia Provider Forum and Dementia Action Alliance. And from people with dementia and carers at regular 'Living Well with Dementia' Roadshows.

Gender & Age

- Younger people are about half as likely to be diagnosed with dementia as older people
- The impact of young onset dementia on families is different to late onset and the costs of non-intervention are likely to be greater than anticipated
- The issues faced by younger people and their families are complex and rapidly changing and they need different information, guidance and support
- Younger people value, above all, continuity of support and someone to turn to for advice
- The distinctive needs of young person with dementia are all too often lost when services are planned.
- Specialist young onset dementia clinical and post diagnosis services are rare (particularly in the South West) and are in decline (Alzheimer's Society 2016)
- Women are more likely to develop dementia because they live longer, they are also more likely to be carers although the proportion of carers who are men increases with age.
- Awareness of appropriate care, with carers, of people with complex progressed dementia, living in a care setting.

Ethnicity

The Alzheimer's Society predict an expected seven-fold increase in 40 years of people with Dementia from BAME backgrounds compared to just over a two-fold increase in the numbers of people with dementia across the whole UK population in the same time period. Despite this,

the All Party Parliamentary Group on dementia has found that people from BAME backgrounds are less likely to receive a diagnosis or support.

Anecdotally, from comments made during the consultation and from feedback from the 'Happy Memories' local event, held locally in 2015, with Chinese and South Asian communities suggests that there is lower awareness, higher levels of stigma and different cultural understandings of dementia from at least some BAME communities.

- Higher levels of undiagnosed dementia in BAME communities due to stigma and lack of awareness and understanding about the disease.
- Distorted and mixed messages about dementia in BAME communities due to different cultural understandings of dementia.
- Lack of referrals from BAME groups due to inadequate diagnostic assessments.

Learning Difficulties

- We need to understand and be able to meet any need for additional specialist services for older people with learning disabilities and dementia.

Gender Reassignment

- People with dementia and carers who are trans may face particular challenges in caring and meeting the needs of loved ones.

Sexual orientation

- People with dementia and carers who are lesbian, gay and bisexual may face particular challenges in caring and meeting the needs of loved ones.

Section 4 - EqlAA Outcome

Outcome	Response	Reason(s) and Justification
Outcome 1: No major change required.	<input type="checkbox"/>	
Outcome 2: Adjustments to remove barriers or to better promote equality have been identified.	<input checked="" type="checkbox"/>	Adjustments have been identified as a result of this EqlAA – please see the table below for details of these adjustments.
Outcome 3: Continue despite having identified potential for adverse impact or missed opportunities to promote equality.	<input type="checkbox"/>	
Outcome 4: Stop and rethink.	<input type="checkbox"/>	

Protected Characteristic	Adjustments and Rationale
Age [Children and Young people 0 to 19; Older People 60+]	Awareness of appropriate care, with carers, of people with complex progressed dementia, living in a care setting.

	<p>Increased awareness of young onset dementia and an improved diagnosis pathway for people with young onset dementia.</p> <p>Bespoke information and support for young people with dementia.</p>
<p>Disability Physical Impairment; Sensory Impairment; Mental Health; Learning Difficulty; Long-Term Condition</p>	<p>Understand the links between sight loss and dementia and ensure appropriate information and support is available.</p> <p>Provide comprehensive information and support for people with dementia and learning difficulties and their carers.</p>
<p>Gender Reassignment [Trans people]</p>	<p>A person centred approach is needed to take into consideration the individual's needs and perspective.</p> <p>Services and support should be sensitive to trans people, both the person with dementia and their carer.</p>
<p>Race</p>	<p>Continue to work with BAME (including African Caribbean, Chinese and South Asian) communities to increase awareness, increase diagnosis rates and reduce dementia related stigma.</p> <p>Review the diagnostic assessments used in primary and secondary care and whether they are culturally appropriate for BAME groups.</p>
<p>Religion or Belief</p>	<p>In some cases religion is closely associated with cultural and ethnic differences. For others religion, belief or lack of either will not be associated.</p> <p>Religion, belief or lack of either would be taken account of in person centred planning of an individual's care and support.</p>
<p>Sex [Male or Female]</p>	<p>A person centred approach is needed to take into consideration the individual's needs and perspective.</p> <p>When developing initiatives we need to be mindful of the need to meet the needs of men as a minority group.</p>
<p>Sexual Orientation</p>	<p>A person centred approach is needed to take into consideration the individual's needs and perspective.</p> <p>Services and support should be sensitive to an individual's sexual orientation, both person with dementia and carer.</p>
<p>Carers</p>	<p>It is important that needs of person with dementia and all carers are both considered.</p> <p>Caring for someone with dementia can adversely impact upon a carer's physical and emotional health.</p>

	We need to ensure that there is information and support in place to fully support carers.
Marriage and Civil Partnership	No negative or differential impact currently identified.

SECTION 5 - ACTIONS TO BE TAKEN AS A RESULT OF THIS EqIAA

The actions from the EqIAA have been incorporated into the dementia and carers strategy action plans which will be reviewed six monthly at the Dementia Planning Groups and Carers Advisory Partnership:

1. Awareness of appropriate care, with carers, of people with complex progressed dementia, living in a care setting.
2. Increased awareness of young onset dementia and an improved diagnosis pathway for people with young onset dementia.
3. Bespoke information and support for young people with dementia.
4. Understand the links between sight loss and dementia and ensure appropriate information and support is available.
5. Provide comprehensive information and support for people with dementia and learning difficulties and their carers.
6. Ensure that services and support are sensitive to sexual orientation and trans people, both the person with dementia and their carer.
7. Continue to work with BAME (including African Caribbean, Chinese and South Asian) communities to increase awareness, increase diagnosis rates and reduce dementia related stigma.
8. Review the diagnostic assessments used in primary and secondary care and whether they are culturally appropriate for BAME groups.
9. Ensure that person centred planning takes account of religion, belief or lack of belief in an individual's care and support plan.
10. Be mindful of the need to meet the needs of men as a minority group when developing and reviewing services and initiatives.
11. Ensure that there is information and support in place to fully support carers physical and mental health.

This strategy will be reviewed in 2019.

SECTION 6 - EVIDENCE INFORMING THIS EqIAA

1. Alzheimer's Society, 2014. Dementia UK: Update.
2. JSNA South Glos - <http://edocs.southglos.gov.uk/completejsna/pages/adults/dementia/>

3. Alzheimer's Society population data - https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=412
4. Alzheimer's Research - <http://www.alzheimersresearchuk.org/wp-content/uploads/2015/03/Women-and-Dementia-A-Marginalised-Majority1.pdf>
5. Meeting the needs and expectations of younger people with dementia, Alzheimer's Society, 2016