



Healthcare
Improvement
Scotland

An Equality Impact Assessment of

SIGN 168: Assessment, diagnosis, care and support for people with dementia and their carers

1. Introduction

Healthcare Improvement Scotland is required to assess the impact of applying a proposed new or revised policy, against the needs of the general equality duty, namely the duty to:

- Eliminate unlawful discrimination, harassment and victimisation and any other conduct prohibited by the Equality Act 2010;
- Advance equality of opportunity between people who share a protected characteristic and people who do not share it; and
- Foster good relations between people who share a protected characteristic and people who do not share it

The relevant protected characteristics are:

- age
- disability
- gender reassignment
- pregnancy and maternity
- race
- religion and belief
- sex
- sexual orientation
- marriage and civil partnership (relates to the elimination of discrimination only)

The recommendations made in this report seek to improve equality and to help meet the specific needs of people with the relevant protected characteristics, where possible.

Our impact assessments also consider if the SIGN guideline on Dementia has the potential to impact on health inequalities.

Health inequalities are disparities in health outcomes between individuals or groups. Health inequalities arise because of inequalities in society, in the conditions in which people are born, grow, live, work, and age.

Health inequalities are influenced by a wide range of factors including access to education, employment and good housing; equitable access to healthcare; individuals' circumstances and behaviours, such as their diet and how much they drink, smoke or exercise; and income levels.

The potential impact of the SIGN guideline on Dementia on an individual's human rights has also been considered.

Giving due regard to these factors is also intended to help Healthcare Improvement Scotland to meet its duties under the Fairer Scotland Duty, which requires public bodies to reduce inequalities of outcome caused by socioeconomic disadvantage.

2. Aim/Purpose of the guideline

To develop an evidence-based guideline on the most appropriate management of people with dementia to reduce variation in practice across NHS Scotland.

In doing so, the guideline seeks to reduce the risk of inequalities in the protected groups discussed in section 4.

3. How we gathered information

Patient and carer perspective

Patients/people with lived experience and carers may have different perspectives on healthcare processes and outcomes from those of healthcare professionals. The involvement of patients and carers in guideline development is therefore important to ensure that guidelines reflect their needs and concerns and address issues that matter to them.

Prior to the initiation of this guideline the SIGN patient involvement advisor invited a number of voluntary organisations to identify issues of importance for patients and carers, this included: Alzheimer's Scotland, Alzheimer Scotland's National Dementia Carers Action Network, Carers Scotland, Carers Trust Scotland, Carer Voices (The Alliance), tide, Age Scotland, About Dementia, LGBT Health and Wellbeing, Life Changes Trust, the Scottish Dementia Working Group, Alzheimer's Society, Young Dementia UK, MECOPP, Scottish older people's assembly. Not all these organisations made a submission, some charities supported this by sharing resources/signposting us to websites where patient stories were.

Common issues raised by patients/people with lived experience and carers groups, included:

- Diagnosis – communicating and disclosing the diagnosis
 - Who should communicate diagnosis of dementia?
 - Information lacking at diagnosis
- Support/education and training
 - Support and training for carers
 - Education and training for healthcare professionals, (particularly GP's and hospital staff). The Dementia Champions Programme was identified as being helpful.
- Post-diagnostic support for those with dementia and carer
- Information and communication
 - Communication with people and families
 - Information needs throughout care
 - Communicating with people with advanced dementia
- Follow up
 - Review appointments – how often and involvement of person with dementia
- Co-production and equality
 - Equal partnerships and involvement of person with dementia
- Transition between settings and support
- Physical activity
 - Keeping people mobile in care settings

- Age of onset of Dementia
 - Young-onset dementia
- Impact of Covid-19

These issues were shared with, and considered by, the Guideline Development Group.

Collecting lived experience data

With a view to integrating patient and carer experience into the development of the SIGN dementia guideline a range of resources highlighting experiences were identified. These included published reports and websites from a wide range of organisations, Tide, Alzheimer's Scotland, Age UK, Young Dementia UK, The Alliance, Alzheimer's Society, Age Scotland Dementia Forum, Life Changes Trust. The video, audio and written experiences provided rich and diverse information but few resources outlined specific methodology. The approach taken by SIGN was to identify and extract themes, information and quotes from published qualitative syntheses and where possible cross-reference these with online patient experiences, stories and resources. Many of the key themes identified mirrored those from the consultation. There is an extensive qualitative literature in the area of dementia examining a wide range of aspects of experience. Examples of commonly identified themes are detailed below.

For people with dementia:

- Living with change and striving for continuity
- Acceptance or avoidance
- Coping, participation, sense of agency and identity
- Relationships, connectedness and hope
- Loss, isolation and loneliness
- Frustration and confusion
- Stigma

For younger people with dementia

- Delays to diagnosis/misattribution of symptoms
- Biographical disruption, finding acceptance
- Uncertainty, adaptation and coping
- Reduced participation
- Loss and self-identity
- Shock, anger, sadness, frustration and anxiety
- Stigma and exclusion

For people with dementia living in nursing homes

- Boredom and monotony
- Loss of identity
- Maintaining freedom and choice
- Meaningful relationships
- Mobility and independence

For informal carers

- Role changes, financial worries
- Crisis, acceptance, adaptation

- Personal satisfaction and hope
- Stress, loss, guilt, obligation
- Social isolation
- Frustration around formal support

For sexual minority people

- Double stigma, an added challenge
- Anticipated and experienced homophobia/discrimination
- Safety and concealment
- Recognition of same-sex partnerships

For people from ethnic minority groups

- Deficits in knowledge of professionals and community members
- Lack of awareness of services
- Stigma, denial and concealment
- Lack of trust
- Cultural appropriateness of services

For people with dementia and their carers during COVID-19 pandemic

- Separation and loss
- Confusion, despair and abandonment
- Stress and exhaustion

Summaries of the qualitative literature and consultation were considered by the Guideline Development Group at the initiation of the guideline and will be throughout the guideline development process to consider what matters to people with dementia and their families/carers. The information/discussion points included in this guideline are intended to aid shared decision making.

Evidence

There are few large scale studies that have investigated social inequalities in dementia, it is recognised, that health inequalities persist into old age and that many of the risk factors for dementia are associated with socio-economic disparities in mortality and morbidity (<http://www.healthscotland.scot/health-topics/dementia>).

4. Protected characteristics

Age

Dementia risk increases with age. Estimated prevalence rates increase from 0.1% of people under the age of 64 years to 15.9% of people aged over 80 years.

Disability

Dementia rates are higher amongst people with a learning disability and onset is often younger. Up to 75% of people with Down's Syndrome over 50 years of age develop dementia. For people with other causes of learning disability the prevalence of dementia is estimated to be greater than 18% in those aged 65 years or over, approximately three times higher than in the general population.

The Guideline Development Group highlighted that work in underway around sensory impairment, [deafness and dementia work](#), to explore culturally appropriate support interventions for deaf carers of people living with dementia.

Gender Reassignment

We did not receive any evidence or findings in this domain.

Marriage & Civil Partnership

We did not receive any evidence or findings in this domain.

Pregnancy & Maternity

As dementia primarily occurs in older adults, pregnancy and dementia would be a very small sub population, as per the steer of this Guideline Development Group Chair. The issues potentially to consider in relation to pregnancy and early onset of dementia could include considerations of undergoing genetic testing ([How Should Clinicians Counsel a Woman with a Strong Family History of Early-Onset Alzheimer's Disease about Her Pregnancy?](#)). Issues around pregnancy were not highlighted as a key issue for this guideline.

Race

The estimated prevalence rates for dementia in the black and ethnic minority community are similar to the rest of the population with the exception of early on-set (presenting before 65 years) and vascular dementia which have been found to be more prevalent. Commonly identified themes for ethnic minority groups are also identified in the section above, lived experience data.

Religion or Belief

We did not receive any evidence or findings in this domain.

Sex

67% of people with dementia are women, most likely because women live longer than men.

Some specific issues for trans people, which are noted in this recent toolkit on dementia and the LGBT community: [Proud to Care: LGBT and Dementia - Scottish Care](#).

Sexual Orientation

The needs of LGBTQ+ people and trans people may differ from those of the general population. This may impact the way in which treatment may be tailored to their needs.

[LGBTQ+: Living with dementia \(alzheimers.org.uk\)](#) highlights additional challenges and considerations such as:

- ▶ Memory problems making it more difficult to remember who a person has informed of their sexual orientation or gender identify
- ▶ The importance of planning ahead, including making advanced decisions and advanced statements to record choices and wishes that will be protected as the disease affects capacity and memory

Dementia care and the LGBTQ+ communities are highlighted in a national care forum report of 2016 'While LGBTQ+ people with dementia share some of the same experiences as heterosexual people living with dementia, there will be many issues that are not the same. As other research has underlined, LGBTQ+ people with dementia have specific health needs along with the usual care and support issues as everyone else as they age. (<https://www.nationalcareforum.org.uk/wp-content/uploads/2019/10/Dementia-care-and-LGBT-communities.pdf>)

For example, the challenges highlighted in our initial piece of work include:

- ▶ People worrying about being forced “back into the closet” in later life because of the attitudes of care staff
- ▶ LGBTQ+ older people being more likely to be estranged from relatives and lacking family support, which makes formal care even more important than it is for their heterosexual peers
- ▶ Some people losing their inhibitions due to dementia, while others who have previously come out feel unable to be open about their sexuality or transgender status
- ▶ The anguish and confusion caused by dementia being exacerbated as LGBTQ+ people with the condition struggle to deal with negative perceptions of their sexuality or gender in residential care.'

Other themes for minority groups are identified in the section above, lived experience data.

Guideline Group Members identified the [RCN guidance on expressing sexuality](#). This work looks at Older People in Care Homes: Sex, Sexuality and Intimate Relationships and offers discussion and guidance document for the nursing workforce. 'Dementia impacts on all aspects of a person's life including sexual activity. In some individuals it increases apathy thereby reducing sexual expression. In others dementia increases disinhibition. It is useful to remember however that, in most people there is a reserve of a continued need for intimacy and interest in sexual satisfaction'. The Guideline Development Group considered issues related to sexuality and Dementia at the first Group meeting and considered one of the key issues was consent and to explore the possibility of influencing the Mental Health Act to include the issue of sexual consent in dementia as the best way forward.

Socio-economic

We did not receive any evidence or findings in this domain.

Island communities

We did not receive any evidence or findings in this domain.

General findings

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 (http://www.healthscotland.scot/media/1226/27797-dementia-and-equality_aug16_english.pdf). It is known 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 need (http://www.healthscotland.scot/media/1226/27797-dementia-and-equality_aug16_english.pdf).

A report and recommendations by The National Advisory Group, [Dementia and equality – meeting the challenge in Scotland](#) highlighted key themes to take forward - continue to raise awareness, ensure robust services and support pathways, ensure appropriate knowledge and skills, and research.

4. Recommendations

The following actions were recommended.

1. Consider producing a patient/carer booklet and/or video for the guideline specifically for young people with dementia.
2. To encourage individualised care, ensuring that beliefs, cultural values, and/or co-morbidities, need to be considered when reviewing the evidence and forming recommendations with respect to the benefits/harms of a treatment, and the acceptability of the treatment to the patient.

Individualised care was a term used by stakeholders that centres on the individual person, rather than generic ‘person-centred care’ which can often be thematic or generalised, eg music therapy – which may not be welcomed by every individual.

3. Consider the specific needs of people who are LGBTQ+ with dementia at the first Guideline Development Group meeting.
4. During consultation, ensure the draft guideline is circulated to LGBTQ+/minority groups/organisations to seek feedback.

5. Monitoring and review

Recommendation	Update/actions taken
1. To encourage individualised care, ensuring that beliefs, cultural values, and/or co-morbidities, need to be considered when reviewing the evidence and forming recommendations with respect to the benefits/harms of a treatment, and the acceptability of the treatment to the patient.	The Guideline Development Group has considered all aspects and the resulting guideline references inequality dimensions, a focus on patient and carer involvement in decisions and the need for individualised approaches.
2. Consider the specific needs of people who are LGBTQ+ with dementia at the first Guideline Development Group meeting.	Gaps were highlighted in the first Guideline Development Group meeting leading to further engagement with LGBTQ+ representative bodies. The following groups were approached before the first group meeting: Alzheimer Scotland, Alzheimer Scotland’s National Dementia Carers Action Network, Carers

Recommendation	Update/actions taken
	<p>Scotland, Carers Trust Scotland, Carer Voices (The Alliance), Together in Dementia Everyday (Tide), Age Scotland, About Dementia, Life Changes Trust, the Scottish Dementia Working Group, Alzheimer’s Society, Young Dementia UK, Minority Ethnic Carers of People Project (MECOPP), LGBT Health and Wellbeing and the Scottish Older People’s Assembly.</p> <p>The following is included in section 1.1.7:</p> <p>For lesbian, gay, bisexual, trans, queer (or sometimes questioning), and others (LGBTQ+):</p> <ul style="list-style-type: none"> • Double stigma, an added challenge • Anticipated and experienced homophobia/discrimination • Safety and concealment • Recognition of same-sex partnerships <p>For people from ethnic minority groups:</p> <ul style="list-style-type: none"> • Deficits in knowledge of professionals and community members • Lack of awareness of services • Stigma, denial and concealment • Lack of trust • Cultural appropriateness of services <p>We have added the following into the resources in section 9.4.2:</p> <p>LGBT Health and Wellbeing A guide to support health and social care staff to develop their practice in working with lesbian, gay, bisexual and trans (LGBT) people with dementia. www.lgbthealth.org.uk/resource/lgbt-dementia-toolkit</p>
<p>3. During consultation, ensure the draft guideline is circulated to LGBTQ/minority groups/organisations to seek feedback.</p>	<p>Organisations including equality organisations were notified of the open consultation and invited to the national meeting. There were the ones listed in the guideline but also other ones such as LGBT Foundation and Race Equality foundation.</p>

Recommendation	Update/actions taken
	<p>Groups such as Age Scotland and Alzheimer’s Scotland have LGBT subgroups so we asked them to ensure they were aware of this opportunity.</p> <p>Feedback was considered by the Guideline Development Group in revisions to the guideline.</p>
<p>4. Include a recommendation for research stemming from the lack of evidence in postdiagnostic support for minority groups and those with protected characteristics</p>	<p>Section 11.2 includes:</p> <ul style="list-style-type: none"> • Research into the experiences of postdiagnostic support in minority groups, those with protected characteristics, those with young-onset dementia and young carers.

The guideline will be subject to peer review and editorial. It will be reviewed in three years for new evidence which may impact on the existing recommendations.

6. Who carried out the impact assessment

EQIA completed by – Sarah Florida-James (Programme Manager) and Alan Bigham (Programme Manager) with input from Karen Graham (Public Involvement Advisor).

EQIA reviewed by – Roberta James (SIGN Programme Lead) and Rosie Tyler-Greig (Equality and Diversity Advisor).

7. Contact Information

If you have any comments or questions about this report, or if you would like us to consider producing this report in an alternative format, please contact SIGN at sign@sign.ac.uk.