**Alzheimer Scotland's response to the Proposed Right to Palliative Care Bill consultation**

**About Alzheimer Scotland**

Alzheimer Scotland is Scotland's national dementia charity and was established in 1980. Our aims are to prevent, care and cure dementia, and ultimately make sure nobody faces dementia alone. We have been raising awareness of dementia and campaigning for the rights of people with dementia for over 40 years. We provide support, advice and information to people living with dementia, their families and carers through our local and national services and activities, including through our Brain Health and Dementia Resource Centres in 25 different locations across Scotland and our 24-hour Freephone Dementia Helpline.

Alzheimer Scotland has more than 8,000 members and we are supported by over 1,000 volunteers. We employ around 400 full and part-time staff, mainly in our service provision projects across Scotland, including our invaluable networks of Dementia Advisors and Post-Diagnostic Support Link Workers.

**1. Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care?**

**X Strongly agree**

□ Partially agree

□ Neutral (neither support nor oppose)

□ Partially disagree

□ Fully disagree

□ Unsure

**Please explain the reasons for your response, including what you think a right to palliative care should deliver.**

Alzheimer Scotland strongly agrees that there should be a legal right to palliative care for terminally ill people in Scotland. We agree with the principles laid out in the proposals and recognise that the delivery of the right to palliative care provides a platform to ensure that human rights for those with terminal illnesses are recognised and upheld.

We recognise that dementia is a progressive, life limiting syndrome without curative treatment and that palliative care should be made available to those with a diagnosis of dementia when they learn of their condition. Dementia is characterised by a prolonged decline in cognitive, psychological and physical function which can take weeks, months or years, but will ultimately result in death. Due to the unique experience of dementia, it is difficult to predict the course of dementia for each individual affected by the condition and to predict when a person will reach the advanced stage of dementia. Predicting the end of life period for a person with dementia is further complicated by the lack an agreed definition of advanced dementia. This particular issue must be addressed to ensure the fair and equitable delivery of future provision of palliative care.

Palliative care should focus on improving the quality of life of people living with dementia, including those with advanced dementia. High-quality palliative care must deliver physical, emotional, practical and psychological support from the point of diagnosis that focuses on living rather than dying. This approach to palliative care can improve the management of symptoms associated with dementia, prevent the under- or over-treatment of symptoms, and can also reduce the demands placed on carers and family members in caring and supporting their loved ones.

Specialist palliative care is required to meet the specific needs of people with dementia. The complexity of dementia and its associated symptoms mean that people with a diagnosis often require specialist palliative

care provided by knowledgeable, trained multi-disciplinary teams across a range of settings. This includes care at home, in acute hospital settings, in care homes and in NHS specialist care units. For end of life care, this may also include in specialist palliative care units or hospices. It is essential that palliative and end of life care is delivered holistically and involves all individuals who are relevant to provide the experience of care that is necessary to ensure the experiences and outcomes that are desired by an individual. This may extend to the involvement of medical, allied health, and social care professionals, as well as professionals from other sectors including housing and the voluntary sector. Importantly, individuals with a terminal illness, their families and carers should be involved in planning palliative and end of life care.

We recognise that people with dementia, even those with advanced dementia who experience significant health care needs, are less likely to receive palliative care and support than those with other terminal conditions. The lack of national standards of care for people approaching the end of life and the variability in the delivery of services across Scotland means that experiences of palliative and end of life care differ significantly. This is further confounded by the lack of systemic data gathered on people's outcomes and experiences of end of life care. We believe that making access to palliative care a legal right would compel local authorities and health boards to prioritise palliative and end-of-life provision.

**2. What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care?**

**Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.**

Alzheimer Scotland believes that any legislation relating to the delivery of care for those with a terminal illness must recognise the distinction between palliative care and end of life care. Current approaches to care indicate that palliative care should be available at the point of diagnosing a life-limiting (terminal) illness while end of life care is a form of palliative care for those who are close to the end of life (death). We are keen that any definition makes clear these distinctions and incorporates both terms within the parameters of the care and support to be provided under any future legislation.

The focus of the legislation should place equal attention on the delivery of palliative care and end of life care. There is a risk of focusing on end of life care, particularly in times of crisis or the period of imminent death, to the detriment of care and support which focuses on living well with a condition like dementia, albeit with an increasing level of disability over time. It is important that any provision or intervention delivers care and support that provides the best possible quality of life during the time someone has remaining, rather than simply preparing for death which may be years down the line.

**3. Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings).**

**What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)?**

□ Strongly agree

**X Partially agree**

□ Neutral (neither support nor oppose)

□ Partially disagree

□ Fully disagree

□ Unsure

**Please explain the reasons for your answer, including the impact this proposal could have on particular people if it became law, and if there are any ways you think the proposal could avoid negative impacts on particular people.**

Alzheimer Scotland recognises that fair and equal access to palliative and end of life care should be made available to everyone who receives a diagnosis of a terminal illness, regardless of their circumstances. However, we recognise that the current experience of accessing palliative and end of life support means that many people with dementia have worse experiences of healthcare, and outcomes at the end of life.

Dementia affects people from all walks of life, including people of all ages, socio-economic backgrounds and cultures. The provision of palliative care must consider the circumstances of each individual who may need care and support following their diagnosis and towards end of life. This should take into account meeting the needs of individuals as well as reflecting their wishes and preferences for how they experience their care and support.

In Scotland, women represent two-thirds of people with a diagnosis of dementia and dementia is the leading cause of death among women. Women are also more likely to provide care for someone with dementia. It is vital that approaches to palliative and end of life care reflect the specific experiences and needs of women.

People in lower socio-economic groups are less likely to be able to access healthcare and people living in poverty are also less likely to engage with palliative care or ask for help. Given that this disparity exists within society, it is essential that this issue is addressed to ensure the fair and equitable delivery of services and supports that reaches out to vulnerable groups.

Additionally, options for palliative and end of life care must reflect the wide and varied cultures that are represented across Scotland. Culturally appropriate care and support should be available to support individuals and families regardless of their ethnicity.

People living with dementia are likely to experience co-morbidities, particularly as they age, and this often results in more complex palliative care needs that require specialist palliative care. Additionally, the choice of where to receive palliative and end of life care is often unavailable to people with dementia since the default position for those with more complex care needs that cannot be managed at home is in care homes, as outlined in Alzheimer Scotland's *Commission on the Future of Long Term Care* report. Although the place of care and death is one of the most important measures in the experience of palliative and end of life care, this option is often removed from people living with dementia despite their commonly expressed desire to remain in their own homes. This issue must be addressed to improve the long term care of people with dementia and other complex care needs, including palliative and end of life care.

**4. What is your view on how a right to palliative care should be implemented?**

**For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented.**

**Please explain the reasons for your response.**

Legislative responsibility for delivering palliative care currently falls to the Integration Authorities yet the system is clearly complex and fragmented. The lack of a cohesive national strategy and a disjointed approach to local delivery plans means that palliative and end of life care remains inconsistent and leaves many vulnerable individuals subject to a 'postcode lottery'. This results in significant variation in the

experience of, and satisfaction with, palliative care services across Scotland. Alzheimer Scotland therefore supports the introduction of minimum palliative care standards that should be adopted at pace across the country, including the right to early intervention and planning which are key to delivering person-centred care. This should be set out at a national level but must co-exist with local delivery plans to ensure consistency.

Given that the delivery of palliative care services is the responsibility of a number of bodies and organisations, it is clear that responsibility for delivering palliative care must encompass an integrated approach that presents all providers with an opportunity to engage in strategic planning and a supportive approach to operational delivery. With the development of joined-up national and local strategic plans, it may be appropriate for reformed Integrated Joint Boards to assume responsibility for palliative care to be delivered against a set of agreed principles standards, while seeking input from groups made up of palliative care providers who can input on specific issues. Clarity is required around the make-up and operational function of reformed Integration joint Boards to explore this opportunity further.

**5. Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability?**

**Please explain the reasons for your response.**

None.