

**The Alzheimer Society of Ireland submission to the Joint Oireachtas Committee on Assisted Dying  
12<sup>th</sup> February 2024**

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to make a submission to the Joint Oireachtas Committee on Assisted Dying. We believe the Committee should consider the following when making legislative and policy recommendations:

1. The fear and stigma associated with dementia.
2. The risk of inaccurate positioning of the person with dementia as a burden on their families.
3. The significant risk that assisted dying becomes an alternative to robust dementia services and supports and quality palliative care. The committee must consider *assisted life* as well as assisted death.
4. The requirement to engage directly with people living with dementia and those who care and support them, to ensure the lived experience of dementia has the power to influence any legislative or policy change.
5. The need to take a rights-based approach to the lives of people with dementia and value their lives avoiding an ableist lens.
6. The progress that has been made in recent years on the provision of support to people impacted by dementia and hope for the future.
7. Safeguarding in the context of cognitive decline and fluctuation.

**1. The fear and stigma associated with dementia.**

In the Oireachtas, the media, and public discourse, we have heard the genuine fears people have about developing dementia. We are concerned that this fear is contributing to a damaging narrative around dementia. Stigma is pervasive and compounds barriers to accessing supports and services, which may support the person to live well for longer, delays help-seeking, and contributes to human-rights

violations of people with dementia [1 - 4]. Common stereotypes include all people with dementia having symptoms which are in fact typical of late-stage dementia, and people with dementia not being able to do anything for themselves, being totally dependent on other people and having no quality of life. This can lead to negative value judgements about their lives and the lives of their families [5]. Needs, wants, preferences, and values fluctuate and change over time, and it is essential that we do not impose our current value system on what we imagine life to be like with dementia.

There is no doubt that dementia is a devastating diagnosis and life-changing illness, but appropriate action and investment in services and support, can help ease the journey and support both people living with dementia and carers to live as well as possible for as long as possible. New services and increased investment bring hope to the landscape of dementia in Ireland which can counteract the fear around diagnosis.

## **2. The risk of inaccurate positioning of the person with dementia as a burden on their families.**

Caring in Ireland has long been associated with poor health outcomes such as stress, burnout, and illness [1,6,7]. ASI research undertaken with 597 family carers in 2023 [1] highlighted that:

- 31% of informal carers rated their mental health as poor;
- 38% of informal carers said they were struggling to cope with their caring responsibilities;
- Almost one third of informal carers spend over 80% of their time supporting a person with; dementia (equating to over 134 hours per week).

Worrying narratives have developed around ‘burden’ in the discourse on assisted dying and we are concerned this could evolve into the idea of assisted dying alleviating carer stress. It must be acknowledged that the person with dementia is not the cause of carer burden. There are not enough supports and services required to meet the needs of people with dementia and family carers are left to make up the shortfall [8].

Informal carers of people with dementia require wrap-around supports including dementia-specific care for their loved one. In fact, evidence suggests that such supports and an optimal mix of participating in psychoeducational interventions incorporating skills training, psychological therapies, and counselling can have highly positive effects on caregivers of people with dementia [9]. It is imperative that the Committee does not accept a scenario whereby the life of a person with dementia and whether they

should consider assisted dying, is presented in the context of the impact of their condition on family members.

### **3. The risk that Assisted Death becomes an alternative to Assisted Living.**

There is a significant risk that assisted death could become an alternative to robust dementia services and supports and quality palliative care. Dementia is a progressive and complex condition that requires support. ASI research [1] illustrates that people living with the condition need a suite of responsive services such as homecare, day care, support groups, activity clubs, and psychological support, and that there is considerable unmet need throughout the country.

The ASI believes that people living with dementia have a right to assisted life. It is not possible to speak about assisted death or dying with dignity without interrogating whether people impacted by dementia have the assistance they need to *live* with dignity. It is critical to consider how societal barriers and challenges that prevent people with dementia from living a full life can contribute to the perception that they cannot enjoy dignity, autonomy, and fulfilling lives.

The provisions of the United Nations Convention on the Rights of Persons with Disabilities [10] promotes the principle of equity. This is reflected in the concept of ‘reasonable accommodation’, which is described as consisting of: “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others all human rights and fundamental freedoms” (CRPD 2006, §5.3<sup>1</sup>). As a society, we must open up local communities, prioritise the implementation the Model of Care for Dementia in Ireland [11] and invest in person-centred supports and services to accommodate people living with dementia to *live* with dignity.

There is compelling evidence that the care of people with dementia, especially towards the end of their lives, is suboptimal [12, 13]. A palliative approach in the care of people with dementia, particularly in the advanced stage, is recommended but not always taken [14]. According to the World Health Organisation, access to timely palliative care is associated with improved quality of life for people with a life-limiting illness [15]. Many people with dementia towards the end of life have numerous emergency

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<sup>1</sup> <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-5-equality-and-non-discrimination.html>

hospital admissions which can be difficult and distressing; however, access to palliative care has been associated with reduced attendance at emergency departments by people with dementia [16,17]. Ensuring that people with dementia and their families understand the benefits of palliative care is essential to make informed decisions about healthcare [18]. Similarly, Advanced Care Planning has been shown to improve end-of-life outcomes, including dying in their preferred place, and having fewer hospitalisations, increased satisfaction with care, and less physical and emotional distress [19].

#### **4. Requirement for Meaningful consultation.**

The cognitive symptoms of dementia may result in those living with the condition being stigmatised, unheard, and forgotten by policy makers, researchers, and society. Swaffer [20] calls this *prescribed disengagement*. It is vital that the Committee engages directly with people living with dementia and their supporters to understand their views on assisted dying. As an organisation, The ASI is already aware that there is not a consensus among people affected by dementia on the matter of assisted dying, meaning consultation should be robust and inclusive.

In all The ASI's positions, including issues relating to end-of-life, matters are viewed and understood through a human-rights lens and led by principles of personhood and dignity. The ASI's Charter of Rights for People with Dementia [21] calls for greater participation, accountability, equality, empowerment, and legal recognition for the rights of people with dementia. Specifically, the Charter states, "*People with dementia have the right to full participation in care needs assessment, planning, deciding and arranging their care, support and treatment.*"

The ASI would be pleased to support the Committee to engage directly with people affected by dementia.

#### **5. Rights-based approach to dementia and ableism.**

The cognitive symptoms of dementia can put a person at risk of human rights violations. Cahill [22] points out that many people with dementia experience '*inequality, marginalisation, discrimination, social exclusion, and at the extreme social oppression*'. If the structures of society do not take a rights-based approach to the lives of people with dementia, the members of that society may place less value on those lives.

The discourse around assisted dying places a lack of value on the lives of people with dementia, it has an ableist lens which, in some cases, can be construed as presenting assisted dying as a solution to cognitive disability. It would appear, the current conversation around assisted dying could lack balance and would seem to be dominated by cognitively well people who cannot imagine a life with reduced cognition.

## **6. Progress on dementia services and supports.**

We are at a critical juncture in dementia in Ireland and one of immense opportunity to deliver the Dementia Model of Care and the framework it provides. The level of dementia service provision in Ireland is increasing, communities are becoming more inclusive, and disease modifying therapies are close to being available. The landscape of living with dementia is changing and improving rapidly. This positive momentum includes improved care outcomes and improving palliative care for people living with dementia<sup>2</sup>.

The ASI asks the committee to contemplate the future of dementia care, not the past, as it considers Assisted Dying.

## **7. Safeguarding concerns in the context of cognitive decline and fluctuation**

There appears to be a dearth of evidence regarding the effectiveness and standardisation of safeguards in the process of assisted dying. Dementia is a complex condition, involving cognitive decline, and cognitive lucidity that can fluctuate dramatically, even from moment to moment. Furthermore, some people living with dementia lose insight into their condition over time. Consent and expressed intentions and wishes, can change and alternate among people with dementia.

This cohort represents a vulnerable group, and there are fears that vulnerable people could be coerced into agreeing to end their own lives or feel that they are burdensome to family and society. There are also concerns that assessments of a person's capacity to decide could be inadequate or inappropriate. Therefore, it is essential that safeguards are given in-depth consideration, particularly considering the complexity and challenges of dementia.

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<sup>2</sup> <https://pallcare4dementia.com/the-project/>

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