

For the attention of the Oireachtas Committee on Justice,

On behalf of The Alzheimer Society of Ireland, I present a submission to the Committee on the Dying with Dignity Bill 2020.

It is imperative that people living with dementia are involved in a meaningful way in the development of policy and legislation in relation to end-of-life matters. This Committee should consider the lived experiences of people with dementia, and their wishes and preferences as it undertakes assessment and scrutiny of the Bill. This will inform the work of the Committee as it strives to assess the Bill from various perspectives.

The Alzheimer Society of Ireland is willing to appear in public session at a Committee meeting to discuss in greater detail the issues outlined below and the lived experiences of people with dementia on the issues that affect them. I would appreciate your consideration of the issues and concerns enclosed.

Yours sincerely,

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Submission to the Committee on Justice

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to make a submission to the Joint Committee on Disability Matters. Our position is informed by The ASI's Charter of Rights for People with Dementia¹, and the needs and vulnerability of people living with dementia.

Context: Dementia in Ireland

Before progressing to the issues of this Submission, it is important to understand the context of dementia in Ireland. The number of people living with dementia in Ireland is approximately 64,000, and this figure is expected to rise to 150,000 by 2041². While dementia is not a normal part of the ageing process, age is the main risk factor. Accordingly, the prevalence of dementia is very much connected to Ireland's ageing population. Those with dementia are also very likely to be ageing with another chronic, sensory or physical disability. There is also a high prevalence of dementia among those who have an intellectual disability. Significantly for this Committee to be aware there is also a significant cohort of younger people living with dementia, those aged under 65 years, totalling approximately 4,200³ people.

Dementia is not an illness in itself, rather an umbrella term used to describe a range of conditions that have similar symptoms, enough to interfere with activities of daily living, and are progressive in nature. Symptoms of dementia range from memory loss, to time and space disorientation, changes in reasoning and motivation, communication difficulties and sensory and functional difficulties. Dementia can affect a person's capacity to give informed consent, manage their finances, live independently, and make a will. Symptoms differ from person to person and no two people will experience it in the same way. With this in mind, while mental capacity will be affected by dementia, it differs for each individual and the person's mental capacity can fluctuate across time.

In addition, a person's physical, social and emotional circumstances will affect the experience, also their personality and existing familial and friendship relationships have an impact. There is no cure for dementia and as a progressive condition, the supports and care people require change; requiring an increasing range of individually tailored and integrated responses (Department of Health, 2014)⁴.

Increasingly, people with dementia are expressing a desire to avoid being defined solely in relation to dementia and to continue to be considered as valued members of society. This is particularly important as the term dementia can have negative connotations. While such stigma has reduced somewhat thanks to public awareness campaigns such as *Dementia: Understand Together*, on which the ASI is a partner, neurological

¹ Irish Dementia Working Group and the Alzheimer Society of Ireland (2016) *A Charter of Rights for People with Dementia*. <https://www.alzheimer.ie/getattachment/About-Us/Policy/Human-Rights/A-Charter-of-Rights-for-People-with-Dementia/Charter-of-Rights-for-People-with-Dementia.pdf.aspx>

² Health Atlas Ireland, 2020.

³ O'Shea, E. Cahill, S. and Pierce, M. (2017) *Developing and Implementing Dementia Policy in Ireland*. NUI Galway.

⁴ Department of Health (2014) *The Irish National Dementia Strategy*. Dublin: DoH.

impairment may interfere with people's day-to-day abilities, coping skills, the emotional and psychological impact of dementia, and access to timely and good quality support. The reactions of relatives, friends and fellow citizens are important, as well as society's response to dementia.

A 2019 report, 'Loneliness and Dementia'⁵, produced by The ASI, recommends that people living with dementia should be enabled to continue to engage in meaningful social activities they enjoyed doing before their dementia diagnosis, should they wish to do so. The report highlights engaging in meaningful activities and social connections as key to combating social isolation and loneliness. However we have yet to achieve a society that empowers older people with choice and control in this way. Given the lack of sufficient and appropriate supports and services for those living with dementia, which can be seen as structural stigma, this societal response reflects an approach that can impact on any personal decision making.

Safeguards & Capacity

The Dying with Dignity Bill provides for people with progressive terminal illness to decide the timing of their own death and avail of assistance to end their lives under controlled and monitored circumstances. Crucially, a person who says that they want assistance to end their own life must have the **capacity** to do so, something which would also be assessed by medical practitioners. If a person meets these criteria and then wished to end their own life, they must state their clear intention to do so and sign a declaration in the presence of a witness, which would also have to be signed by two medical practitioners.

The Bill contains safeguards relating to capacity to ensure a person would be qualified to make a decision to end their own life including,

- At the first stage, the two medical practitioners would also have to verify the person's terminal illness and **assess their capacity to make the decision to end their own life.**
- ***Those who cannot understand or retain information about ending their life or those who cannot communicate their decision to do so would not be allowed to request assistance.***

ASI Position

In all ASI's positions, including issues relating to end-of-life, matters are viewed and understood through a rights lens, and therefore, are led by principles of personhood and dignity. The ASI's Charter of Rights for People with Dementia 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."

⁵ Hartigan, I., Park, G., Timmons, S., Foley, T., Jennings, A., Cornally, N., Muller, N., (2019) Loneliness and Dementia. Produced by The Alzheimer Society of Ireland.

The will and preferences of people with dementia should be paramount, and this can be understood through meaningful engagement and conversation with people affected by dementia in order to elicit their preferences and wishes. The voice of the person with dementia and their carers should be strengthened, and their wishes should be reflected in all of the treatment and care they receive, whilst dignity and person-centredness should be respected at all times.

ASI Concerns

Dementia is a complex condition, involving cognitive decline and cognitive lucidity that can fluctuate even on daily basis. 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 critical that the safeguards contained in this Bill are given in-depth consideration, particularly in light of the complexity and challenges of dementia.

As the safeguarding criteria in the proposed legislation shows, assisted dying is an extremely complicated process and there are worries that it could be open to abuse. There are concerned that the legislation might have unintended consequences that might create adverse impacts on vulnerable people.

Questions have been posed as to whether assisted dying is a solution to suffering in a society that offers palliative care, where people can die in a dignified and painless manner. Another argument asks whether more investment in this kind of treatment is required, rather than legislating for a process that is far more complicated. Ethical considerations also play a part, and whether or not the practice is compatible with medical ethics and the role of doctors to heal, rather than harm, those they treat.

Notably, members of the Irish Palliative Medicine Consultants' Association (IPMCA) have called on TDs to oppose the Dying with Dignity Bill saying no change in the law is required. The doctors say they are gravely concerned by any proposal to legislate for assisted suicide and euthanasia in Ireland, and believe that it poses a threat to healthcare in Ireland, to the true meaning of the doctor-patient relationship and to the future of what we know as compassionate and supportive specialist palliative care. They have also expressed concern about the impact on people who already struggle to have their voices heard in our society – older adults, the disabled, those with mental illness and others. Members argue that as dying with dignity is already present within healthcare in Ireland, no change to our current laws is required.

It does not appear that there has been adequate opportunity to consult on the Bill, and charities and NGOs involved in the ageing sector who have been concerned with COVID-19 issues and impact have not had adequate time or opportunity to input into the debate and consultation on this issue. We are of the view that the consultation process should be extended to give adequate time to consult people with dementia and family carers, for example members of the Irish Dementia Working Group and the Dementia Carers Campaign Network. This would help ensure that the voices of those affected by dementia are included in a meaningful way.

The ASI calls on the Committee for Justice to seek that draft legislation is written using a rights-based lens and to ensure there are mechanisms and supports to ensure that the voices of vulnerable people are included at all stages.

Ends.