Call for input by the Independent Expert on the enjoyment of all human rights by older persons, on "Autonomy, participation and human dignity of older persons with cognitive impairment"

The Alzheimer Society of Ireland Submission

6 June 2026

The Alzheimer Society of Ireland (The ASI) is the largest dementia-specific service provider in Ireland, supporting people living with dementia, their families and carers through a wide range of community-based services and supports. The ASI's vision is society where people on the journey of dementia are valued, can realise their rights and exercise choice, and are living well where they choose.

Dementia is a syndrome caused by a range of progressive brain diseases, the most common of which is Alzheimer's Disease. It is characterised by a progressive loss of cognitive and functional abilities, often impinging on quality of life and the ability to live independently. Alzheimer Europe (AE) estimates that 69,949 people are currently living with dementia in Ireland. AE also reports that there is currently an estimated 9,065,706 people with dementia in the EU, a figure which will increase to 14,335,788 by 2050.[1] As the most significant risk factor for dementia is ageing, dementia mainly affects older people.

Living with dementia can impact a person's enjoyment of human rights in various and profound ways. This submission first outlines The ASI's perspectives on how dementia affects the autonomy, participation, and human dignity of older persons, and secondly highlights good practices and recommendations to support and uphold these rights. Beyond this submission, The ASI welcomes further opportunities for engagement with the OHCHR on this issue.

1. The Impact of Living with Dementia on the Autonomy, Participation and Human Dignity of Older Persons

[1] Alzheimer Europe (2026) Prevalence of Dementia in Europe 2025. Luxembourg: Alzheimer Europe. Available at: <https://www.alzheimer-europe.org/sites/default/files/2026-01/alzheimer_europe_-dementia_prevalence_report_2025-final-_digital.pdf> (Accessed: 29 June 2026).

Impact on Daily Activities and Independence

The impact of dementia extends far beyond cognitive symptoms. Difficulties with everyday activities such as managing medications, organising oneself, preparing meals, handling finances, driving, attending appointments and navigating familiar environments can significantly reduce independence. Over time, people with dementia require assistance with personal care and other activities of daily living, increasing reliance on informal and formal care supports. In 2023, The ASI conducted a national study, *The Experience of Dementia in Ireland*, which captured the perspectives of 72 people living with dementia and 597 family carers. One respondent outlined their experience of living with dementia as follows: *"I am no longer self-sufficient, can't remember how to do basic tasks."*

For many people, the loss of independence associated with dementia is one of the most feared and distressing aspects of the condition. Activities and responsibilities that were once routine become increasingly challenging, resulting in a gradual loss of autonomy and confidence.

Impact on Social Participation

Social participation is deeply affected by dementia. People tend to withdraw from social activities due to cognitive difficulties, reduced confidence, practical barriers or stigma. Activities that once provided enjoyment, purpose and connection can become increasingly difficult to access or sustain.

The ASI's research consistently demonstrates the importance that people living with dementia place on maintaining meaningful activities, social connections and a sense of identity following diagnosis. However, many individuals report barriers to participation and a lack of appropriate opportunities and supports. For example, in The ASI's national research in 2023, one person living with dementia reported *"I used to be very actively engaged with all local groups GAA, active retirement, community alert, historical committee… But when I was diagnosed with dementia, all that stopped because I thought it was the end."* Another family carer stated that their family member living with dementia *"was asked not to come back to her local community group."* This withdrawal from social participation can contribute to loneliness and isolation for the person living with dementia. This is also deeply concerning as social participation is essential for brain health.[2]

Awareness and Stigma

Stigma, lack of dementia awareness, and discrimination all play a part in these issues, leading to both those diagnosed with dementia and carers withdrawing from their usual

[2] Gill Livingston, Jonathan Huntley, Kai Liu and others, 'Dementia Prevention, Intervention, and Care: 2024 Report of the Lancet Standing Commission' (2024) 404 The Lancet 572.

social activities and limiting their interactions with local communities. Some carers discussed this further in our national research, including one respondent experiencing *"[a] lack of simple contact with others dealing with dementia – stigma is part of this."* Another stated in relation to their parents: "[the diagnosis] *is a huge strain on us all…It has devastated us completely and we find that many people avoid Mam and Dad because they don't know how to deal with it."*

Impact on Family and Personal Relationships

It is estimated that for every one person diagnosed with dementia, three people in their close circle are significantly impacted. Family members frequently assume caregiving responsibilities, often resulting in changes to established roles and dynamics within families. Caring responsibilities place significant demands on spouses, partners, children and other relatives, affecting family life, social participation and overall wellbeing. Findings from our national research demonstrate that both people living with dementia and family carers experience unmet support needs and challenges accessing appropriate services. Family carers report balancing caregiving responsibilities alongside employment, parenting, financial commitments and their own health needs. The progressive nature of dementia places considerable and growing emotional and practical strain on family relationships over many years.

Impact on Finances

The financial impact of dementia can reduce autonomy, participation and human dignity by limiting access to supports, restricting social and community involvement, and increasing dependence on others. This impact for an individual is significant, with the cost of dementia care ranking higher than stroke, heart disease and cancer. It carries significant financial consequences for both individuals and families, arising from additional care, healthcare, transport and household costs.

The impact on employment also extends to family carers. The Irish health and social care system is dependent on family carers who provide the majority of care to people with dementia. Many reduce working hours, take extended leave or leave the workforce entirely in order to provide care and support. These changes have lasting consequences for household income, financial security and pension accumulation. A clear pattern of financial hardship was found in The ASI's national research with one respondent describing the financial hardship on their household as: *"Going without. Late payments on bills. Needing to borrow."*

In addition to lost income, families face increasing costs as the disease progresses. Expenses may include private home care, transport, healthcare appointments, assistive technologies, home adaptations and other disease-related costs. The combined impact of rising expenses and reduced earning capacity can place considerable financial strain on households affected by dementia. One respondent to The ASI's national research in

2023 described feeling *"fear as [the] disease progresses [and] what options we will have [as] full-time care is too expensive"* with another experiencing *"uncertainty about the future and how to fund care."* Research published by The ASI and Family Carers Ireland in 2022 and later research in 2023 found that more than half of family carers of people with dementia reported difficulty making ends meet, with many reducing spending on essentials, social activities and household expenses as a result of their caring responsibilities.

2. Recommendations and Examples of Good Practice

Supporting People Living with Dementia to Remain at Home for Longer

The ASI has consistently highlighted the importance of dementia-specific home support, day services and post-diagnostic supports to support people to remain living at home and staying connected to their communities for as long as possible. This is consistent with the preferences as well as the human rights of people living with dementia under Article 19 UN Convention on the Rights of Persons with Disabilities. It is well-established that it improves wellbeing and quality of life by enhancing opportunities for social connection, cognitive stimulation, meaningful activity, and holistic psychosocial support. This helps maintain independence, identity, connection to community, and reduces isolation.

Championing the Lived Experience

Including the lived experience of people with dementia in advocacy, research and policy ensures that activities, services and policies are informed by those directly affected, helping to uphold autonomy, promote meaningful participation, and protect the human dignity of individuals living with dementia.

The ASI supports two self-advocacy groups which aim to ensure that the voice of people with lived experience of dementia is central to our work and activities. They are involved in a wide range of work and activities. This includes awareness raising activities, challenging stigma, influencing policy and practice, contributing to healthcare education, engaging with political and community stakeholders, supporting ASI initiatives and fundraising, and sharing lived experiences of dementia nationally and internationally.

(a) Irish Dementia Working Group (IDWG)

The IDWG is a group of people living with dementia who advocate for better services, supports, and policies in Ireland. The IDWG members meet to share experiences and highlight issues that are important to them. It is a space to do something proactive and positive and bring purpose to life after diagnosis. The IDWG is working to improve life for

people living with dementia throughout Ireland. The ASI supports the group, and their work is overseen by a Steering Group comprised of people living with dementia.

(b) Dementia Carers Campaign Network (DCCN)

The DCCN is a group of people with experience of caring for and supporting someone living with dementia. It aims to represent and amplify the voices of dementia carers across Ireland, while raising awareness of the issues and challenges faced by families living with dementia. The group is supported by The ASI and their work is overseen by a committee of 10 family carers and supporters.

Charter of Rights for People with Dementia

The ASI has worked consistently to advance the rights of people living with dementia by championing their lived experience to achieve rights-based policy and law reform. A key element of this was the publication of a **Charter of Rights for People with Dementia** ("the Charter") in April 2016 with the IDWG. The Charter calls for greater participation, accountability, equality, empowerment, and legal recognition of the rights of people with dementia.

Adult Safeguarding in Nursing Homes

While there has been an increased focus on ageing in place for older people, for some people, including people living with dementia, nursing home care may be required to adequately meet their care needs as their dementia progresses and care needs increase. Nursing homes are the homes of many people living with dementia who should be supported to enjoy a good quality of life, maintain and develop relationships, and contribute to society. However, institutional and organisational practices within nursing homes can restrict residents' privacy, dignity, choice and independence, while also limiting opportunities for social engagement and participation in meaningful activities. In a Briefing Paper commissioned by The ASI in 2022, *"Adult Safeguarding & People with Dementia in Nursing Homes"* (annexed below), a series of recommendations were set out for nursing homes to address these issues. These include:

- Promoting a human rights-based approach
- Supported decision-making
- Promoting agency and identity
- Creating dementia-friendly environments
- Ensuring meaningful participation
- Supporting relationships and family life
- Using restraint-free and person-centred care

Assisted Decision-Making (Capacity) Act 2015

Supported decision-making is an important step in respecting the autonomy, participation and human dignity of older persons with cognitive impairment, including people living with dementia. Ireland's Assisted Decision-Making (Capacity) Act 2015 (ADMCA) was signed into law on 30 December 2015 and commenced on the 26 April 2023. It establishes the legal framework for supported decision-making in Ireland. A number of the principles underlying the ADMCA merit highlighting here as important examples of good practice, including:

- A person is presumed to have capacity unless it is shown otherwise.
- A decision is only made for a person when it is necessary.
- A decision made for a person must be the least restrictive of their rights and freedom.
- A decision must respect the person's right to dignity, bodily integrity, privacy, autonomy and control over their own affairs.
- A person should be permitted, encouraged and facilitated to participate in any action/intervention taken for them.

Capacity is assessed using a functional test, which recognises that a person may communicate their decision through a range of methods, including speech, writing, sign language, assistive technology, or any other means.

Conclusion

Dementia can significantly affect the autonomy, participation and human dignity of older persons through cognitive changes, stigma, social exclusion, financial hardship and increasing reliance on care and support. However, a diagnosis of dementia should never diminish a person's rights, voice or value. The ASI believes that people living with dementia must be supported to exercise choice, participate in decisions that affect their lives, maintain meaningful relationships and remain connected to their communities. Achieving this requires a human rights-based approach, access to dementia-specific services and supports, supported decision-making, and the meaningful involvement of people with dementia in policy and service development.