



Opening Statement by John Dunne, Chief Executive to the Joint Committee on Health hearing on the needs of persons with dementia and the services available to them (7th February, 2024)

Cathaoirleach,

On behalf of Family Carers Ireland, I would like to thank the Committee for giving us the opportunity to address the health needs of persons with dementia and the services available for them. I am joined by Clare Duffy, our Policy & Public Affairs Manager.

We are pleased to be appearing with the Alzheimer's Society of Ireland. We have long history of cooperation in supporting families caring for someone with dementia. Five of our basic on-line courses covering generic caring issues are on the HSE Dementia-Pathways portal¹; we have our own basic e-learning module on dementia-care²; our online Carer Forum offers a virtual peer support network for carers of people with dementia³; and all of our crisis supports, including counselling and emergency respite, are available to carers of people with dementia.

A good deal of our research is of relevance to dementia care. In particular, in 2021, we partnered with Dr Emma O'Shea of UCC's centre for gerontology & rehabilitation to research the factors that support resilience in families supporting someone with dementia/influence the sustainability of family caregiving in the context of dementia⁴. That report concluded that almost half of the cost of dementia care is attributable to the opportunity cost of care provided by the family and that we need to give families care options if we are going to propagate the 'ageing-in-place' dogma. Following that report we collaborated with ASI in researching the financial challenges facing families caring for people with dementia in Ireland, following an analysis of feedback provided by family carers of people with dementia as part of our 2022 State of Caring report.

Generally speaking, we see our core competence as rooted in the practicalities of caring, including providing generic personal care and we defer to ASI on issues relating to dementia itself. As an organisation Family Carers Ireland consciously focuses on the family carer precisely because too often carers don't realise until it's too late that if they don't look after themselves they won't be able to keep looking after anyone else. In that context, I'd like to mention the upcoming referendum about family caring (regardless of the condition of the person) and the need for recognition, value and real tangible supports and services to make their lives easier. Family Carers Ireland sees the referendum as important for enshrining recognition and value for family care in our constitution. Having said that, it would have been helpful in countering widespread disappointment with the watering down of the recommended wording from the Citizens' Assembly to have made some further progress on the roll-out of the Carer Guarantee in 2024 as evidence of the state's 'striving' to support family carers.

Focussing on the caring dyad rather than the condition is a different perspective to the one framed in a national dementia strategy. Dementia is challenging but many of the specific challenges it

¹ <https://www.hse.ie/eng/dementia-pathways/education-and-training/knowledge-skills-development/>

² <https://familycarers.ie/courses/dementia-care/index.html#/>

³ <https://forum.familycarers.ie/caring-for-a-person-with-dementia-867724>

⁴ https://familycarers.ie/media/2344/3-emmashea_fci-conference_sustaincare-221121.pdf

presents – changing relationships, personal care, flight risk, carer harm – are not specific to dementia and present on a spectrum that must be calibrated alongside the internal resilience and external supports the caring individual or family can draw upon. Before she died my mother developed delirium on top of relatively mild dementia. The diagnosis made little practical difference – there is no national delirium service – and for me the syndrome mattered less than the sudden, significant changes in her situation that had to be managed on a day to day basis.

For the avoidance of doubt I'm not arguing that our focus on the care situation is superior to the condition-based one, merely that, as reflected in the effective partnership we have with the Alzheimer's Society of Ireland, the two are complementary. We fully support the development of a national dementia strategy but we would like to see it – along with a family carer strategy, a positive ageing strategy, a mental health strategy, a drugs strategy – being developed in the context of integrated social care strategy, all informed by a holistic model of integrated care focussed on the changing needs of patients and their family carers.

Between 2012 and 2015 the Health Service Executive (HSE) and Genio co-funded four innovative local projects with a view to demonstrating how people with advanced dementia and complex needs could be enabled to live fulfilling lives in their community and prevent avoidable residential care or hospitalisation. The projects offered a 12-week intervention providing additional, flexible and responsive home care hours (including over-night respite and weekend cover) as well as telecare devices and other technologies. It incorporated a dementia education programme for home support staff; an education programme for Public Health Nurses and the adoption of the Zarit Burden Interview to assess carer burden. The pilot projects informed the subsequent development of a mainstream Community Supports Model for dementia services and we have continued to partner with the HSE in the delivery of the Living Well with Dementia in South Tipperary since 2015.

A key feature of the pilot programme was personalised supports based on an assessment of the person with dementia and their family carer a unit of care. This was a tremendously important innovation from our perspective. The pilot projects used the Zarit burden scale to assess the subjective burden being experienced by family carers. Without wishing to drag the committee into the details of such tools I would make the point that, in our experience, focussing on burden is a perspective that risks promoting dependence rather than resilience. I am happy to acknowledge that the Department is continuing to explore the best approach to assessing carer need following a recent pilot evaluation of the INTERRAI module in CHO2 and we are actively engaging with them in this endeavour.

An early evaluation of the Genio initiatives noted that whilst the pilots focussed on dementia the learning had the potential to inform the development of many other service areas in Ireland and internationally. The failure to see this potential being realised is disappointing. We share ASI's frustration with the uneven delivery of dementia services and, indeed, many other elements of our health services. This reflects a frequent lack of coherence across the health and social care system. For example, a recent evaluation of the Living Well with Dementia project argued for additional resources for a dementia service that is already significantly better resourced than those in the rest of CHO5.

In that context, I'd like to conclude by repeating a concern that I have voiced to this committee before. Given the experience to date with CHOs and the even stronger focus on regional autonomy in Sláintecare how are national services to avoid a post-code lottery in national initiatives such as the Dementia Service – or, indeed, the Carer Guarantee? This will require practical mechanisms – possibly a detailed service specification to each Chief Officer – informed by appropriate strategies – I refer back to the concept of a single integrated Social Care strategy mentioned earlier.