



The Alzheimer Society of Ireland: Opening Statement for submission to JHC

Long statement (for publication)

Good morning, my name is Adrienne McAvinue. I am a Homecare Coordinator with The Alzheimer Society of Ireland (ASI).

I began my career 21 years ago with The ASI as a homecare worker and I have seen first-hand what works and what doesn't in homecare for people living with dementia.

I know that homecare has the power to radically improve the lives of people with dementia and their families and supporters. Our organisation welcomes this opportunity to speak to the committee about dementia-specific homecare.

Dementia demographics

Of the 64,000 people living with dementia in Ireland, the majority, 63%, live at home in their own communities.

180,000 people in Ireland are caring for a family member or partner with dementia with many more providing support and care in other ways. The importance of family carers to the overall health and social care system in Ireland cannot be underestimated.

The overall cost of dementia care in Ireland is just over 1.69 billion euro per annum. 48% of this is attributable to family care and 43% is accounted for by residential care. Formal health and social care including home care services contribute only 9% to the total cost.

The National Dementia Strategy

It is the preferred wish of most people with dementia to continue living in their own homes for as long as possible in a familiar environment linked to their communities.

In December 2014, the Irish government published its first National Dementia Strategy, which supports this preference. The Strategy states that: "People with dementia should be facilitated to remain living in their own homes and to maintain existing roles and relationships for as long as possible...". The provision of integrated homecare services is a priority action of the Strategy, which is underpinned by the dual principles of personhood and citizenship. The current 2020 Programme for Government states a commitment to implementing the National Dementia Strategy.

Rising need

The increased prevalence of dementia in Ireland points to a deepening gap between services and need. It's estimated that of the 64,000 people living with dementia today, this number will more than double to over 150,000 by 2045. The need for services is growing, not only among existing

service users but also among those who had not previously been in contact with dementia-specific services following the COVID-19 Pandemic.

Dementia specific homecare

People living with dementia have diverse and specific needs in relation to homecare. Dementia-specific homecare consists of person-centred, consistent, and continuous care, provided by dementia trained staff and in partnership with the person with dementia and their carer, while promoting independence and inclusion. It requires specific competencies and skill sets as most people with dementia who are in receipt of homecare are at the moderate to advanced stage, often presenting with complex needs.

The Alzheimer Society of Ireland provides dementia-specific homecare that involves social stimulation, in addition to support with daily tasks. Such supports are vital because they enable the person with dementia to remain at home in the community for as long as possible without having to move to residential care. Where possible, The ASI attempts to provide longer blocks of homecare hours as this is optimal for people living with dementia (e.g., two hours).

Despite discussion around holistic care, there remains a narrow view of homecare when it comes to assessment. The assessment of need is often focused on tasks such as showering, using the bathroom, climbing stairs etc. The reality is that many people living with dementia need support but are denied this support because they do not require personal care. If any of us in this room were to consider what brings our lives meaning and joy it would probably *not* be limited to the shower and the bathroom. Quality dementia homecare is responsive and most critically it is flexible.

Remuneration

Homecare for people living with dementia is highly skilled yet it is generally low paid and undervalued work. The additional skills and expertise required in delivering dementia-specific homecare are often not reflected in remuneration. There is a critical need to standardise homecare rates of pay and benefits across Ireland. The introduction of approaches to support homecare workers to protect their income and entitlements should also be considered in the context of the COVID-19 pandemic. Many contracts are for a smaller number of hours than the standard 39 hour work week which can hinder organisations in attracting candidates who need to earn a living.

With respect, we have lost countless excellent homecare workers to the organisation that funds us - the HSE. We are doing highly skilled and hard work; we train our teams and nurture them. As the coordinator of a homecare service, it is so disappointing and frustrating when our team members leave for better terms and conditions which our funding will not allow us to offer.

Our struggle to retain staff has a real impact on continuity of care - trust between people living with dementia and their families with their homecare workers is essential. High staff turnover does not facilitate building that trust.

Lone working

Homecare work is most often undertaken by a person working alone. There are risks involved in lone working and a quality of life impact of working in isolation. Homecare workers report missing

camaraderie and social interaction with colleagues, particularly during the COVID-19 pandemic. Due to sparse funding there is no opportunity for our organisation to operate a buddy system (as we would like) or allow new starters to work alongside more experienced staff for a meaningful period of time.

Travel & block hours

Homecare workers are not paid for travel time, and the time spent out working does not reflect the hours in their contract. This challenge is increased in rural areas which requires more travel in between homecare recipients. Similarly, many homecare workers would like to work additional hours, but this is not possible with travel time.

In The Alzheimer Society of Ireland we mitigate this by offering blocks of hours. While it is a solution to the fractured nature of homecare work, it is also quality care. A block of hours gives the person with dementia a meaningful interaction and allows care to be person-centred, not task orientated or delivered in a rushed manner.

Block hours offer the family carer a significant break and they report the ability to shop, exercise and meet friends. This is so important because we know there is a significant negative impact on the physical and mental health of family carers as they care for a loved one with dementia. Indeed, the De-Stress Report - a research study to examine the impact of caring for a spouse, reports 77% of spousal carers had depressive symptoms and 35% had anxiety. This was coupled with significant physical health issues.

What I found most shocking from that report was that 48% of spousal carers reported spending every waking moment caring for their loved one. We need to be very clear - there is a huge burden in being a carer of a person living with dementia. But the burden is not the person with the illness, the burden is the lack of services and supports.

More recently, our COVID Impact Report found that 54% of family carers are struggling with their mental health and 40% are struggling with physical health.

The recent rise in the cost of diesel and petrol is becoming a significant barrier to homecare work that requires the worker to travel between many homes. That coupled with being 'on the road' in all weather and under pressure to make calls at a certain time means that alternative work in a warm nursing home or hospital environment is more attractive.

Upskilling & development

Homecare requires more resourcing in terms of time and investment in professional and personal staff development programmes, in addition to education through practice-based learning.

Due to low funding base, some organisations are unable to offer any non-essential learning and development opportunities to home care workers. This impedes their career progression and results in them leaving to better funded agencies who can offer these opportunities. A standardised training package should be provided for carers across the board with various levels of training provided, so that carers can be allocated to a person based on their needs e.g., a more skilled and trained carer

would be allocated to someone with greater care needs, a carer experienced in care of people with dementia, or end-of life care needs, would be assigned to that person.

Conclusion

To conclude today I want to leave you with one thought.

We must consider how you as policy makers value homecare workers. If I was a bank manager or your financial consultant and was looking after your money, I would be handsomely rewarded. Yet if I was a carer looking after the most precious people in your life, I would be earning just above the minimum wage.

At the end of the day, we either value this work and its people or we don't. In homecare our most valued commodity is our people. I believe we should stop talking about how we value them and instead show them.