

Crowded Isolation and Loneliness: A Perspective from Carers of People living with Dementia



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Executive Summary



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Although I do not regret my decision to care, I had no idea it would be like this.

Caring for someone living with dementia brings with it many challenges to the ability of the carer to live well (Merrilees, 2016). The loss of shared memories, proper communication and a close relationship can make a carer feel lonely, even when their loved one is sitting with them (Quinn, 2020). Research by Victor et al (2020) examined loneliness in a large sample of family carers of those living with dementia. Nearly two thirds of carers (62%) reported loneliness, with 18% reporting severe loneliness.

Although caring for someone living with dementia can be a lonely and isolating experience, your life can, at the same time, feel crowded with responsibility. You are dealing with a variety of different people, systems and reactions, trying to manage so many things and anxious about whether you're 'doing it right'.

Carers of those living with dementia were experiencing crowded isolation and loneliness well before the pandemic and will continue to do so once the pandemic is over, as others return to 'normal'. The pandemic didn't create this experience, it just made it more acute.

This work has been developed and led by carers in Northern Ireland, following the coproduction principles of accessibility; experts by lived experience; collaboration and shared goals; equalising power relations and a focus on impact.

From across the 4 nations, we received 103 responses to the online survey between the 2nd and 25th March 2021. We conducted 29 interviews, either online or on the phone, between 3rd March and 28th April 2021. This was a 'convenience sample' of tide members along with those receiving an invitation to complete the survey from partner organisations.

There were a number of themes prioritised from the research evidence: **family, friends, finances and the future; conversation, connection and self-care; grief and guilt; limbo, loss and lockdown; recognition and support systems.**

Additional areas of interest taken from the interviews included: **the positive aspects of caring; gender, hidden lives, and severe impact on mental health.**

Main Findings: This research adds to existing evidence on loneliness and social isolation experienced by carers of people living with dementia. Main findings relate to:

Family and Friends

- Family relationships and expectations about caring are a significant factor in how the caring role is experienced
- Loss of friendship, social circles and connection with others

Finances and the Future

- Worry about finances, including how to pay for care
- Having to cut down work hours or give up work completely

Mental Health and Wellbeing

- Loss of personal identity as the caring role consumes everything else, including the life a carer used to live and the life they imagined they would have in the future
- The detrimental impact of caring on physical and mental health and the difficulty of taking time to look after your own needs
- Carers having to hide what they feel for much of the time
- A pervasive feeling of guilt that you are not prepared, not doing things right, not wanting the role, not doing enough, not being enough

Specifics of Caring for someone living with Dementia

- Dementia is a disease of the brain, not a mental health condition. The lack of recognition and understanding of the condition impacts on services and on the lived experience of carers
- There is continued stigma attached to dementia and corresponding impact of this on the isolation of carers
- The long-term, unpredictable, progressive and palliative nature of dementia
- The experience of living grief, stemming from loss of connection and intimacy, loss of shared memories, and changes in personality and relationship

Services and Support

- Lack of recognition – in the workplace, health and social care services, by friends and family, in wider society – of the role of family carers and the impact of caring
- Lack of personalised support from health and social care services

Recommendations: We recommend that carers of people living with dementia are:

- Partners in both local and national decision-making through the co-production of commissioning, strategy development, service design, delivery and improvement
- Identified by the health and social care system with a clear carer support pathway, including a key worker at point of diagnosis
- Included as a priority group requiring emotional support services and interventions, such as psychological therapies, in any Dementia Care Pathways, Carers Strategies or Covid Recovery Plans
- At the heart of social care reform that ensure family and friends carers get the practical and financial support they have a right to
- Able to obtain timely, accessible and appropriate respite / carer breaks

To further recognise the rights of carers of people living with dementia, there must be:

- Investigation into and regulation of the cost, consistency and standard of social care, whether delivered at home or in residential and nursing care.
- Professionalisation of social care, including training and qualifications, with corresponding salary scales.
- Recognition of dementia as disease of the brain and a terminal illness that needs corresponding funding, NHS and palliative support
- Resourcing, access to and promotion of peer support
- Recognition of the financial impact on carers in terms of the cost of care and lost earnings, with an uplift in relevant benefits

tide believes in a society where family and friend carers of people with dementia use their voices and society reflects and responds to their unique carer rights. We hope this report goes some way to making that happen.

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Dementia is a health care issue, they call it social care, which is unfunded compared to the NHS, this needs root and branch reform. Critical that dementia care is funded by the government. Nothing less should be tolerated as a point of principle.