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together in dementia everyday

Crowded Isolation and Loneliness:

A Perspective from Carers of People living with Dementia

LOTTERY FUNDED

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HSC

June 2021

June 2021

> I sometimes want to stand on the edge of a cliff and scream at the unfairness of it all.

Thank You

Siobhan Gallagher, Jean Reynolds and Judy Sinclair: The tide members who created, led, delivered and were the drivers for this project from start to finish. Their generosity, humour, honesty, experience and commitment made it happen. It was a privilege to work with these incredibly 'fine' women. They have stood at that cliff edge.

All the carer participants who spent time completing the online survey and being interviewed. Thank you for sharing with us your experiences and your hidden lives.

Sarah Butler-Boycott, Lena O'Connell, Fiona McMahon, Vicki Rutland and Sarah Swift: tide staff whose expertise and commitment supported the project so well.

The Health and Social Care Board for providing the funding that allowed this work to move forward.

We are tide, a network of present and former carers of people with dementia. We work to connect carers with each other; develop opportunities to express how it is to be a carer in creative ways; provide information and skills; and work to influencing for change. Any present or former carer of someone living with dementia can join, for free, and participate in whatever way suits them. If you are interested in finding out more, or perhaps becoming a part of our collective voice, please contact us:

@ carers@tide.uk.net   tide.uk.net

☎ 0151 237 2669   ✉ c/o Age NI, 3 Lower Crescent, Belfast

f @tidecarers   #tide_carers

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> Just that it's hard going at times.

All quotes from carers of people living with dementia are taken from the online survey and interviews conducted in March and April 2021

01.

Executive Summary

> 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.

> “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.

02.

Introduction

This was the description that the tide Carers Steering Group members gave to their experience of crowded isolation and loneliness.

> “I’m surrounded but I’m alone. I’ve never felt so isolated.

Caring for someone with dementia can be a lonely and isolating experience whilst, at the same time, your life feels 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 someone living with dementia have described experiencing a **crowded** mind from all the responsibility; a daily life filled with caring routines and the prospect of an **isolated** future; alienation, as social life and independence disappear; a home crowded with strangers who are not there for you; being **isolated** in the house due to caring responsibilities; an additional sense of **loneliness** if the person you care for isn’t at home any longer; and, if they are at home, ‘no longer there’ as the person you knew.

All this whilst feeling a rollercoaster of emotions, both for the person you care for and for yourself. Ultimately, it can feel that really, you’re on your own.

The term Crowded Isolation and Loneliness came from conversations with tide carers in Northern Ireland. It is not pandemic-specific. Carers of those living with dementia were experiencing crowded isolation and loneliness before the pandemic and will continue to do so once it is over and others return to ‘normal’. The pandemic didn’t create this experience; it just made it more acute. This is a carer’s ‘normal’, everyday experience.

How we did it and what we learnt

We used a co-production approach which involves relationships in which the skills, knowledge and experience of all participants are equally valued and combined in the process of planning and delivering research. This means:

Accessibility: information is co-produced in ways that are accessible, understandable to all involved and available in a wide range of accessible formats.

Experts by Lived Experience: research respects the value of academic, professional and lived experience and knowledge.

Collaboration and Shared Goals: a mutual understanding of what and why the work is being done, including aims, objectives and desired outcomes. This provides a sound basis for equal partnership working.

Equalising Power Relations: carer priorities steer the research process; power and responsibility are shared equally and constantly reviewed; and all partners can influence decisions throughout, with opportunities for reflection and learning from experience.

Impact: research outcomes have intended impact.
(Adapted from Armstrong & Banks 2011)

The Process

The Steering Group Brief (Appendix B) details the set-up for the project. Training in conducting robust research and interview techniques was provided for carers. The Steering Group met a total of 6 times between January and June 2021, with a lot of work in between. Carers were paid a participation fee. The Steering Group decided on the background information and questions for the online survey (Appendix A and C) as well as the interview questions, consent forms and support information (Appendix D, E and F). They decided the priorities relating to the video, animation and report.

103 responses were received for the online survey between 2nd and 25th March 2021. 29 interviews were also conducted by carers, either online or on the phone, between 3rd March and 28th April 2021. Three carers provided video clips of their experiences, with a further two writing their stories.

Learning from Each Other

- The importance of carer-to-carer conversations: this provides a safe environment and an honest channel. Giving carers the time to talk to someone who understands meant they felt they were being heard and contributing to a collective voice.
- A mixed experience for the carer interviewers: Some enjoyed it, had never done anything like this and learnt a lot. Others found it very difficult as recurring themes triggered their own experiences as they also dealt with their caring responsibilities.
- The process: there are pros and cons to phone and video interviews. Timings can be difficult. There is a need to be clear about the time it takes for all involved.
- Meetings are not always the answer. Individual conversations and the accumulation of knowledge and understanding from working with carers can be used to inform the work.

- Calling something 'research' can put people off.
- The importance of clear language and concise information: there is a balance between giving detailed explanation and the time it takes to participate. Be honest about the time it takes - for the carers leading and doing the work, as well as those completing online surveys and being interviewed.

Learning to Share the Evidence

Tide carers chose a variety of ways to share what we found out. They were clear that they wanted different methods to communicate with different audiences and used their own experience of accessing information. Three different methods were used: video, animation, and this report. We hope that these different methods engage different people with the subject.

This report, and the associated video and animation, have come from tide carers wanting to share common experiences, listen to the stories of others, challenge a society that allows this to happen, and provide some positive solutions to change carer's lives. See https://www.tide.uk.net/resources/crowded-isolation-and-loneliness/

03.

Background

> I'm disheartened and I'm lonely. I still want my Mum even if she can't help or console me. In fact, it's the other way round normally. I feel redundant.

Definitions of Loneliness and Social Isolation

A variety of definitions of loneliness and social isolation exist, many of which are ambiguous and the subject of much academic debate. The concepts were being explored as far back as the 1960's & Townsend (1968) noted that 'living alone, loneliness, and social isolation' were often used interchangeably. In the case of loneliness and social isolation, this is often still the case (Cattan et al 2005; Windle, Francis & Coomber 2011; Wigfield at al 2020), although the two concepts have been differentiated by researchers in a number of ways.

In their work on developing a framework for understanding social isolation and loneliness, Wigfield et al (2020) laid out the key differentiating issues that they gleaned from international literature:

- Subjective v Objective: Loneliness can be considered a subjective experience, including feelings about lack of connection with others, even if an individual has social networks, whereas social isolation is an objective count of social interactions (Dykstra, 2009).
- Quantitative v Qualitative Relations: Social isolation can be determined by the number of social contacts, whereas loneliness can be determined by the quality of those contacts (Peplau & Perlman 1982; Pettigrew & Roberts 2008; Segrin & Passalacqua 2010, Green et al 2001)
- Actual v Desired Contacts: Loneliness has been described as the mismatch between the amount of social interaction a person has compared to what they want
- Negative v Positive Perception: Social isolation is not necessarily negative and can be experienced as a positive, but loneliness is always felt as a negative
- Voluntary or Involuntary: The matter of individual choice is important and, although someone can choose to be socially isolated, if they have no say in the matter, this can lead to loneliness. (Dickens et al 2011; Newall et al 2009 & 2014)

- Acquaintances v Deeper Friendships: Social isolation can be quickly alleviated through social contact with new acquaintances, whereas loneliness can take much longer to address as it relies on the formation of intimate bonds. (Dickens et al 2011)

Loneliness and social isolation, then, are related but distinct concepts. Loneliness is an individual's personal sense that they are lacking quality relationships, closeness and social contact with others. Social isolation refers to a lack of contact with family or friends, community involvement or access to services. It is, therefore, possible to be lonely in a crowd without being socially isolated and equally possible to be socially isolated without feeling lonely (Aiden 2016).

Causes and Impact of Loneliness and Social Isolation

Social isolation and loneliness can be experienced by anyone. This is a health inequality issue because the degree of risk depends on a number of inter-related factors causing some groups and individuals to be more vulnerable than others. As Durcan & Bell (2015) point out, analysis of the broader concept of social exclusion shows how people can become disconnected from social groups as a result of economic, social and cultural factors. Popay et al (2008) note that processes leading to social exclusion are embedded in unequal power relationships, interact across cultural, socio-economic and political dimensions, and operate at individual, community, population and global levels. This is why interventions to reduce social isolation need to act on structural determinants, including economic disadvantage and discrimination, as well as supporting the immediate needs of socially isolated and/or lonely individuals.

Along with economic, social, cultural and political factors, key transition points across the life course can also increase the risk of loneliness and social isolation. In its 2016 report, the British Red Cross identified factors such as becoming a parent, leaving education, leaving care, becoming a full-time carer, becoming unemployed, the break-up of a relationship, retirement and bereavement as increasing this risk (Aidan, 2016).

Research shows the impact on health of loneliness and social isolation, with both morbidity and mortality increasing (Hawkley & Cacioppo 2010, Holt-Linstad at al 2010). Social isolation has been found to be as strong a risk factor for morbidity and mortality as smoking, obesity, a sedentary lifestyle and high blood pressure (House et al 1988), and the impact of loneliness on cognition has been linked to cognitive impairment and decline, increased risk of dementia, and an increase in depressive symptoms (Shankar et al 2013, Holwerda et al 2014, Hawkley & Cacioppo 2010)

Loneliness, Isolation and Family Carers

Based on data from its members, Carers UK (2015) estimate that 8 out of 10 carers in the UK have felt lonely or socially isolated as a result of their caring role, and the Office for National Statistics (2018) reported that people with caring responsibilities were 37% more likely to report loneliness than those without. The UK government Loneliness Strategy identifies family carers as a group who are potentially vulnerable to loneliness (DCMS, 2018), and a range of factors underpin that vulnerability.

Carers UK identified that, as a result of their caring role, 57% of carers had lost touch with family and friends, 49% had difficulties in their relationship with their partner, 38% felt isolated from colleagues at work, and 54% struggled to pay bills due to the extra costs of caring and potential fall in income. Carers reported feeling as if no-one understood their situation, with some aspects of caring, such as personal care, being very difficult to talk about whilst still respecting the dignity of the cared for person. Feeling responsible, often solely so, for the person they cared for, had an impact on emotional wellbeing; and some carers also reported stigma, lack of awareness and hostility from the general public (Carers UK 2015).

Research indicates that carers have higher levels of stress and depression, and lower levels of subjective wellbeing than those without a caring role (Pinquart & Sörensen, 2003; Verbakel, 2014). They also encounter a greater risk of developing physical health problems (Vitaliano et al. 2003), particularly those carers who experience mental distress and/or face behaviours that challenge from the cared-for person (Pinquart & Sörensen, 2007). The carer role can restrict carers' participation in social activities (Clark & Bond, 2000) thus limiting the psychological benefits that accessing social support offers (Cannuscio et al., 2004) as well as the opportunity for a satisfying social life.

Organisations contributing to the Welsh government review on the impact of loneliness and social isolation on health and wellbeing (Owens & Sirois, 2019) reported that those caring for over 30 hours a week are more likely to be socially isolated simply because they can't get out to see their friends or family. They don't have the time to socialise and invitations to participate reduce over time. Carers frequently reported that they 'feel invisible', even when visitors come to the house because they have come to see the cared for person, as opposed to the carer. The report 'Loneliness in Northern Ireland: A Call to Action' (Quinn, 2020) noted similar issues, and also noted that people who care for a partner can experience changes in the relationship dynamic, leading to loneliness.

Vasileiou identified, in 2017, that although much academic research had talked about loneliness as an issue for carers, there was little evidence attempting to understand this in depth. Vasileiou's study, therefore, aimed to examine the reflections of family carers on experiences of loneliness linked to their caregiving situation. The research identified the linked themes of less personal space and social interaction imposed by the caring role; lack or loss of social and personal relationships; and feelings of powerlessness, helplessness and a sense of sole responsibility.

Family Carers of People Living with Dementia

Loneliness and isolation have been explored in a range of populations, but very few focus specifically on carers of people living with dementia. This is surprising, given that the estimated number of family carers in this situation is approximately 700,000 (Lewis et al, 2014). Life expectancy for someone living with dementia can vary between 5 and 12 years depending on the type of dementia. In the early stages of the disease, the person may be fairly independent and able to do most things with only a little help, with care needs becoming greater as the dementia progresses.

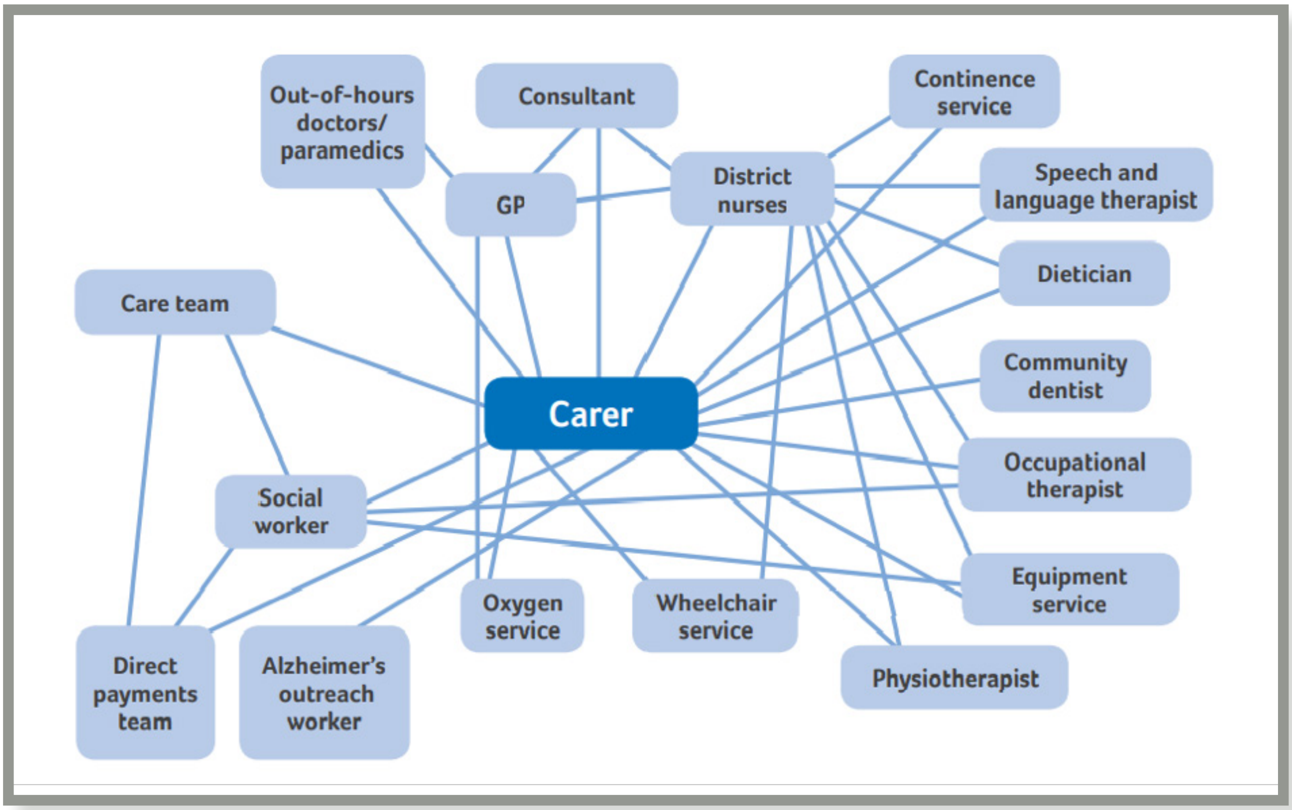
Carers might, therefore, provide care for a long period of time, but the level of care required may vary as their loved one's condition deteriorates. This means that people living with dementia have care needs that are different to, and often greater than, those with other long-term health conditions (Prince et al, 2013) and, compared with both the general population and carers supporting those with other illnesses, carers of people living with dementia often experience poorer quality of life (Garzon-Malonado et al, 2017; Koyama et al, 2017; Pinquart & Sorensen, 2003).

Caring for someone living with dementia brings with it many challenges to the ability of the carer to live well, with impacts including loss and grief, isolation and loneliness, depression, anxiety and exhaustion, and the challenge of balancing care provision with other responsibilities and the carers own health problems (Merrilees, 2016). A 2003 study of 49 family carers indicated that those looking after someone living with Alzheimer's reported greater loneliness and depression in comparison to people with no caring role, and that loneliness was predictive of depression (Beeson 2003). 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), as part of the IDEAL Study, was one of the first large-scale attempts to examine loneliness in a large sample of family carers of those living with dementia, examining both the prevalence and predictors of loneliness. Nearly two thirds of carers (62%) reported loneliness, with18% reporting severe loneliness. Their findings indicated that greater social isolation, increased stress and poorer wellbeing were associated with loneliness; that better quality of current relationship reduced the risk; and that male carers were more likely to report loneliness than female carers.

The Carers Northern Ireland and Marie Curie report, 'Lost Retirement' (2018) notes that caring for someone with a terminal illness can have a significant financial impact. Carers may have to leave work or reduce their hours to fulfil their caring role, with many excluded from welfare support. This can increase loneliness and stress and, in some cases, push carers into poverty, leaving them unable to afford essentials such as food and heating. For many, the effects of caring continue long after their loved one has died, with the impact on their health and wellbeing lasting for months or even years afterwards.

The report also noted that, despite carers spending so much of their time interacting with health and social care professionals, opportunities to talk about themselves and their own health needs are often missed or become an afterthought.



Adapted for Carers NI/Marie Curie 'Lost Retirement' Report (2018) from The National Council for Palliative Care (2013) Who Cares? Support for Carers of People Approaching the End of Life.

Impact of the Covid-19 Pandemic

The Covid-19 pandemic has placed an almost intolerable level of stress on carers of people living with dementia and exacerbated the many existing issues in health and social care services for both. The effects on carers in terms of the additional practical demands, impact on physical and emotional health and wellbeing, the lack of support available, and the isolation and loss felt by many have been striking.

Research has highlighted the significant impact of social support & service closures. The fact that many support groups stopped resulted in loss of support, as well as respite and downtime for family carers (Giebel et al 2020a, Giebel et al 2021). It was also noted that carers were faced with making difficult decisions and had to make drastic changes to their own lives in terms of cancelling paid care, moving in with the person living with dementia, and working from home whilst caring full-time, all while family and peer support was unavailable (Giebel et al 2020a). Carers said that the loss of support they were able to access previously contributed to feelings of loneliness, largely attributed to the fact that their main social contact is the person living with dementia that they care for, with limited interaction following a decline in cognition and memory (Hanna, 2021).

In a study looking at the impact of the pandemic on hospital care (NAD/RCPsych 2021), 90% of carers said that they had not been allowed to visit the person they cared for during their admission, with 43% given no explanation about visiting procedures. Many carers commented on the negative impact that reduced visiting had on people living with dementia.

Tide - Together in Dementia Everyday (2020) highlighted in its report that, despite unpaid carers providing the majority of care and support to people living with dementia, the policy focus on them has diminished and many carers have felt that their own needs, as well as those of the person they care for, have been ignored by government and decision-makers. Carers stated that communication and information has been lacking, services and support have disappeared, and coverage and attention on these issues has been minimal. The report also outlined the practical difficulties of getting food, medication and PPE; distress caused by not being able to visit loved ones in care homes, an impact on the ability to provide end of life care, feelings of grief and loss, and the effects of caring 24/7 with limited support as causing stress, lack of sleep, isolation, loneliness, anxiety, worry, and the struggle of having to manage mental health for both themselves and their loved one.

Tide (2020) The Experiences of Carers of People Living with Dementia during the Covid-19 Pandemic.

04.

Themes

> You sort of get used to it, but there is a cost to one’s own health and outlook - subtle but significant.

Having read all interviews and survey responses and quantified the different experiences expressed, 24 themes were identified. The Steering Group chose the emerging themes from this list having read all the surveys and conducted all the interviews. The highlighted themes were chosen to best reflect the experience of the carers who participated.

The themes are interconnected and are grouped to show some of these links.
The experience of each of these impact on the different parts of a carer’s world.

Themes from the online surveys:

- Family, friends, finances and the future
- Conversation, connection and self-care
- Grief and guilt
- Limbo, loss and lockdown
- Recognition
- Support

Additional areas of interest from the interviews:

- Positive aspects of caring
- Gender
- Hidden lives
- Severe impact on mental health

Family, Friends, Finances and the Future

> Diagnosis of dementia at the moment is a tsunami to any family and can shatter close relationships into a thousand pieces.

Carers wrote and talked about their **family** dynamics a great deal. Some carers did not have any family support. Some had family and friend connections that meant the caring role was shared and understood, but one carer said that they didn't want their family to know how they were so 'hid their pain'. When asked about who supported them in their caring role, one person responded:

> My family and best friend. It's good to talk but doesn't change the situation I'm in.

Others felt they had been left by other family members to carry most or all of the caring responsibilities, for a range of reasons. These included fractured family relationships, being the nearest geographically, being single, having no children, an expectation of a daughter's role, and employment situations. Family relationships and who did, or was expected to do, the 'day to day' caring was a significant factor in how the caring role was experienced.

As reported in previous research, many carers lose touch with family and friends, and the caring role can restrict participation in social activities (Carers UK, 2015; Clark & Bond, 2000). During this piece of work, the essential support provided by **friends** was also mentioned, along with the loss of friendships and social circles as the caring role became more demanding and unpredictable. The feeling that people either didn't understand the experience of caring or felt uncomfortable with dementia was expressed. Some carers recognised their loneliness and tried to maintain social interaction but found this an effort. One carer commented:

> I am lonely but have no time or energy for social interaction. I feel as if I'm losing my social network because they cannot understand how draining it all is. I'm lonely, but when I have some free space, ironically, I just want to be alone and have no desire to talk about it.

Worrying about **finances** and how to manage in the present as well as the future was mentioned. Organising how care is paid for; cutting down on work hours or giving up work completely; and not knowing how long the caring role will last, all put pressure on carers. This can lead to further feelings of isolation. One carer commented on the times that they felt crowded isolation and loneliness the most:

> When carers are chatting about new cars and holidays and new clothes, and I need a new pair of slippers and couldn't afford them.

This is in line with previous research that talks about the significant financial impact of caring for someone with a terminal illness and being excluded from welfare support (Carers NI/Marie Curie, 2018). In 2019, Carers UK found that 22% of carers were living in poverty, compared to a national figure of 16% living in relative poverty and with Carer's Allowance being ineffective at preventing financial hardship (Carers UK, 2019).

> I would love to buy a greenhouse when I retire, and I can't because we don't know when or for how long we might need the money. It's about not knowing what will happen in the future.

What the **future** holds is something we all think about, but for carers of people living with dementia this can be difficult. It can be hard to focus on what is ahead when the everyday is all-consuming. However, a number of carers did mention their worries about the future. One carer stated:

> I wish this was not my life. I feel my life slipping away. Worry about what the future holds.

Conversation, Connection and Self-Care

Missing **conversation** and **connection** with the person being cared for was often mentioned. Not being able to communicate with the person you are caring for because of the impact of their dementia means feeling lonely even when they are with you. Your connection is lost in some ways. One carer stated:

> I miss the intimacy we once had, and I crave it as I am very much a physical person.

Conversation and connection with others can also be lost. A report from Carers UK in 2019 noted that 32% of carers did not feel comfortable talking about their caring role with friends, 48% said they didn't have time to spend on social activities, and 49% were unable to leave the house. Conversations with carers during this research revealed that feelings of crowded isolation and loneliness were felt more acutely by some carers at Christmas time, holiday periods and family occasions. A song on the radio or seeing other people enjoying their retirement together can make the loss of connection even more difficult. At a time of crisis, for one carer, the disconnect was obvious:

> Recently I experienced ill health myself. My partner was oblivious to my condition even when the ambulance personnel came to our home.

In response to a question asking what it is they think but don't say about their caring role, one person stated that they can't say:

> How crippling it is. The exhaustion and the pain are unbearable at times.

Carers aren't only carers. They have jobs, children, relationships, dreams, and ambitions. Caring can mean that a person may lose their sense of identity:

> I'm a man's man. The 'go to' guy when things need sorting out. Now I feel like I'm in Groundhog Day. Each day feels like a fortnight but, because I've created no memories, the time seems to have gone quickly. It's a weird feeling. When someone asks how I'm doing, I could burst into tears any time.

In relation to **self-care**, several carers mentioned that talking therapies or counselling had helped them manage their caring role. There was recognition that self-care is essential. There was also recognition of how hard this can be for carers as their lives are crowded with responsibilities. A carer commented:

> Put your own oxygen mask on first. Your tank doesn't run on empty.

The emotional and physical toll on carers themselves was often mentioned. One carer honestly stated they had become 'alcohol dependent'. Another wrote that they wished they had the strength to tell people how they felt. The balancing of different responsibilities over a long period of time was also cited as difficult to deal with and the sense of being overwhelmed by responsibility felt strongly. One person commented that others don't realise:

> How serious the effects of full-time caring can be on mental and physical health. It's impossible to cope on your own without paying a heavy toll. How you don't notice the accumulative affect. Little by little it piles up.

Previous research has suggested that carers experience higher levels of stress and depression (Pinquart & Sorensen, 2003; Verbakel, 2014), & are at greater risk of physical health problems (Vitaliano et al, 2003; Carers UK, 2018). The 2021 Carers Week Report, Breaks or Breakdown, points out that the toll on physical and mental health has been exacerbated by the pandemic, with 35% of carers feeling unable to manage their caring role, and 68% of carers of people living with dementia saying they were unable to look after their own health and wellbeing (Carers UK, 2021).

Grief and Guilt

Living **grief** is a common experience for carers of those living with dementia. There are many layers of grief. There is the sense of losing someone over a period of time and the experience of grief being continual. This can be due to changes in personality, loss of communication skills, loss of shared memories and loss of the relationship you had with them. These feelings need to be managed in the context of still coping with the everyday demands of work, relationship and family commitments as well as caring responsibilities. One carer noted that:

> “(There are) high expectations to work and care and be on top form whilst suffering from anticipatory grief.

There is also grief for the life respondents had been living before becoming a carer, as well as the life they thought they would be living or had planned.

The carer experience of living grief has been reported previously in terms of compounded serial losses for themselves – companionship, personal freedom, and control – as well as for the person living with dementia (Chan et al, 2012; Wijngaarden, 2018), with studies reporting anticipatory grief between 47% and 71%. The experience of living grief is particular to dementia because of the unpredictable and long term degenerative and palliative nature of dementia, and is detailed in tide’s previous work (tide, 2019).

Alongside this, carer **guilt** is prevalent – guilt about not wanting to be a carer, guilt about ‘not doing it right’ even though no one trains you for the role, guilt about the decisions that have to be made, about feeling trapped, and the other areas of your life not given attention because of your caring responsibilities. Previous research concurs that family carers of people living with dementia often describe feelings of guilt. One study also noted the importance of identifying and differentiating between guilt, anticipatory grief, and depression when planning supportive interventions (Gillard Owen & Harrison Dening, 2018).

One carer, when asked about advice they would want to share with another carer, responded:

> That it's not my fault. And no matter what I do I'll never be able to 'fix' things. To be kind to myself and tell myself I'm doing my best. To remind myself that my mum still loves me, and I can celebrate our former relationship. I wasn't prepared for how much would change or how irritating it would be when people who have no idea of the reality of the situation would tell me to take time for myself. I would have tried to prepare myself for the grief.

Most people are not asked if they would like to become a carer; it just happens, either in crisis or over a period of time, until that's what you are.

The long-term, unpredictable and palliative nature of caring for someone living with dementia means that carers can be fulfilling the role for an indefinite period of time and feel that:

> Nothing can prepare you. Every person is different, I have accepted my situation because there is nothing I can do about it.

Limbo, Loss and Lockdown

The idea of living life in **limbo** was mentioned by different carers. Not knowing what your caring responsibilities may be on a daily basis creates a sense of living day-to-day:

> Everyone feels lonely sometimes in life, but as a carer you are immersed in the experience, and it is a constant. It is difficult not to feel as if life is slipping by and you are in limbo.

There is the **loss** of the 'life you used to live', the loss of the relationship you used to have, and the future you imagined. The loss felt through changes in the relationship dynamic between carer and cared for has been noted in previous research and impacts significantly on the experience of loneliness (Quinn, 2020). The loss of connection through work was mentioned as carers talked about their struggles with juggling work or having to reduce hours or give up work completely. When asked about their life before caring one person answered:

> I was lively, adventurous, and creative and loved my life and work. I had a wide circle of friends and enjoyed outings, holidays and social activities.

Some carers lived their lives in a kind of lockdown long before the pandemic because of the restrictions that society and caring put on their everyday lives. Other carers didn't feel that their caring role had changed their lives as much as **lockdown**, and that the pandemic has changed life for everyone:

> I only truly began in this way when the pandemic began. Life isn't the same for anyone. I have a lot of friends, including a good number of close friends, and communicate a lot with people through my job, so I've always sought out solitude to counterbalance. I've never felt lonely.

> Amplified by COVID. I thought I was having a breakdown on a number of occasions, couldn't stop crying.

Recognition

The **recognition of their role** as a carer for someone living with dementia is something that is important to carers and was a topic that came up often. This means recognition of the role and its impact in the workplace, in health and social care, in their circle of family and friends, and in wider society.

> I long for someone to walk the journey with me. There are people around but no one committed and able to stay the course.

> I think I have developed more tolerance and empathy. It's not easy.

The **recognition of dementia** as a palliative health condition was seen as crucially important, as well as an understanding of the condition and its progression. This is an area that is important to carers but not always highlighted in research, although the first study to rigorously describe the clinical course of advanced dementia concluded that it is a terminal illness and is insufficiently recognised as such (Mitchell et al, 2009). This lack of recognition results in less funding for health care of dementia, and people living with dementia not receiving the palliative care that can give comfort to the terminally ill.

> Use the time before their illness progresses to be more prepared. Get as much help and information as possible. I was constantly firefighting and, as the situation got worse, I had no time to myself and no time to seek help. The little time I did have for myself, I couldn't face doing anything. Everything seems ok until it suddenly isn't, and it is too late.

There is also the importance of **recognition of each other** and by organisations such as tide. The support provided by other carers and through carer and dementia organisations was recognised by participants as being significant to carers:

> I recognise the look in others.

> I shared with my Tide group and received great support and advice and I'm aware this journey is only going to get tougher.

Previous research concurs that family carers often feel invisible in their role (Owens & Siroi, 2019). Carers UK reported in 2015 that carers spoke of stigma, lack of awareness and hostility from the general public (Carers UK, 2015). In 2019, Carers UK reported that, despite the high numbers of carers in society, half (51%) of the UK public did not think they had a friend or family member providing unpaid care, with only 39% of the public saying they have at least 1 friend or family member who is a carer (Carers UK, 2019).

Support Systems

Some carers had developed good support systems for themselves. Social workers, Occupational Therapists, Macmillan and Admiral Nurses, psychologists and care home staff were mentioned as sources of support.

However, it was family and friends, as well as carer and dementia organisations that were cited most often:

> I have had support from my friends and family during this period which kept me afloat. Tide has been of great help to me, and various zoom meetings have kept me in touch with other carers who are experiencing similar feelings.

It was found challenging to have to ask for support all the time or even being afraid to ask:

> I wish that someone would offer to give me support without having to ask.

> Very little support, as afraid to look for help.

Frustration at the role and the lack of support from some health and social care services was clear:

> I have been able to get a team of carers, which is of great help, but their management proved difficult.

> People (carers) across the UK are dying inside through being ignored and unsupported financially, resourcefully, emotionally and every which way possible.

Comparisons between Nations:

Differences

One of the questions in the survey asked the respondents to describe the support they receive in their caring role. Carers living in Scotland emphasised that they largely rely on support from family and friends. Some practical support from professional carers or respite was available, but this had been difficult to organise and obtain during lockdown.

Conversely, the majority of carers living in England reported that they received a lot of support from community organisations, various groups and Third Sector service providers. Many carers living in England stated that they were looking forward to restrictions being lifted so that they could continue to receive community-based services and benefit from the support they provide.

Respondents from Northern Ireland spoke of vital support received from family and friends, as well as support services provided by such organisations as Dementia NI, the Northern Ireland Hospice team and Cancer Lifeline.

The majority of care in the UK is provided by family carers; something which social services and the NHS rely on. However, the experience of carers not receiving adequate support from statutory services has been discussed for many years. For example, in 2013, The State of Caring (Carers UK, 2013) reported that 37% of carers said they cared without any support from services or from friends and family; a further 29% cared with support from friends and family, but none from services. This remains something that impacts on the negative experience of cares of people living with dementia.

> She is in a concrete maze; she’s there looking for help but every time she turns a corner there is another concrete wall so she has to turn to find another way and finds more concrete walls and she can’t get out.

Common Threads

In response to the question about how support for the caring role could be enhanced many carers, from all 4 nations, stated that they would like to receive counselling and believed that this would be helpful to them, particularly if received early on in their caring journey. These findings are reflective of other research in this area (for examples see Appendix G). An individual's experience of caring is affected by economic, social, cultural and political factors. Together with the specific experience of caring for someone living with dementia and the recent impact of the pandemic, caring is an emotional and increasingly difficult role, making connection and self-care essential.

> I did have some counselling, but I organised that privately. It was never offered and, even if it had been, I would probably still be on the waiting list. (Carer, Wales)

> If need be, seek help from counsellors or trusted friends who will listen without judgement. I have considered counselling myself. (Carer, England)

> I think I would have benefitted from some counselling support (probably still would). However, when I was the main carer, I prioritised my free time at home with my partner over this – I didn't feel I could squeeze anything else in. (Carer, Scotland)

> I have found the work of carers support very good for training and activities. Some counselling would be beneficial. (Carer, Northern Ireland)

Additional Insights from the Interviews

> I've had a lot of opportunities and a lot of holidays in my life. I have had a lot of freedom and I am only a carer for a short time.

51 of the 103 respondents agreed to take part in a one-to-one interview.

Due to time and capacity, it was not possible to offer an interview to all those who offered. 37 carers were offered a one-to-one interview and 14 were offered the opportunity to attend a focus group. As no one wanted to attend a focus group and some carers were later unavailable, 29 carers were interviewed in total.

Three carers from Northern Ireland conducted the interviews with carers from all 4 nations (11 in Northern Ireland, 9 from England, 4 from Wales, and 4 from Scotland). 22 women and 7 men were interviewed. 13 were caring for parents, 15 for their spouse and 1 was a former carer.

Additional areas of interest from the interviews were:

- Positive aspects of caring
- Gender
- Hidden emotions
- Severe impact on mental health

Positive Aspects of Caring

Caring can be a positive experience for many carers, particularly with adequate support. In their Alone & Caring report, Carers UK (2015) indicated that 7% of carers said it had brought them closer to family and friends, 29% closer to the person they cared for, and 21% described finding new friends through the role. In our research, some carers spoke positively about their caring role. Their feeling was that life was still good; there are moments of joy and connection. A sense of duty, giving back or 'pay back' was expressed:

> Still good moments living with dementia. Relationship was great, it is still good – it hasn't changed. I feel I am more thoughtful.

> It's not all doom and gloom. She reckons theirs is a book yet to be written called 'The joy of dementia'.

> No one imposed it on me. I believe that my parents supported me, and I would like to support my Mum.

Gender

From some of the interview conversations, it became apparent that there was a clearly understood expectation that women in the family would provide the majority of care (as a daughter, wife, single woman, or woman without children). This was assumed and, it was felt, can be hard to escape. The caring role had impacted on women's careers, relationships and sense of self.

> I'll have a future when Dad dies. I was angry or begrudging but now I just don't get attached to the idea anymore.

> I hate this role! It's so hard and nobody really knows what it's like because everyone's pain is different.

> Caring has a huge impact on your career and working life. You never have a minute to yourself as you are always project-managing others.

These findings are in line with previous surveys where it was found that, overall, women are more likely to take on caring roles than men and more likely to be providing care 'around the clock', with 60% of those caring for over 50 hours a week being female. Women are also more likely to be sandwich carers, caring for young children and elderly parents at the same time, and more likely to have given up work or reduced working hours to provide care (ONS, 2011; NHS Information Centre, 2010; YouGov Polling, 2013).

Hidden Lives

The sense of having to hide their true feelings came through in several interviews, with carers not being able to say how they really are and what they really feel. Those carers either couldn't say what they really thought or noted that no one had asked them:

> You'd feel ashamed if anyone could see what you're thinking. And some people think you might be a lovely virtuous person cos you're caring but inside you're constantly resenting it.

> I hate this role! It's so hard and nobody really knows what it's like because everyone's pain is different.

> I felt guilty applying for Attendance Allowance and it was at this point that I realised I was a carer and, if I'm honest, I don't believe I'm very good at it.

Severe Impact on Mental Health

As was also clear from the survey findings, the detrimental impact on carers' mental health was profound. Some of the sacrifices made, coupled with the lack of support and understanding of the role made the experience of caring negative and traumatic. Several of the carers interviewed stated that their caring responsibilities had impacted severely on their mental health:

> I'll have a future when Dad dies. I was angry or begrudging but now I just don't get attached to the idea anymore.

> I still feel detached. I feel that I am in no man's land. I am like a widow, but I am not. I just feel lost as I am neither one nor the other.

> I care for my husband and my son. I had to choose between them – which one to care for – and decided it was better to put my son in a care home, which broke my heart. My life is full of guilt. I am completely burnt out.

06.

Stories: Joanne and Joe

> I would look out the window and wonder what had happened to my life. Then I would go to bed in my old room, and it felt like all the years of being my own person had just drifted away or been some kind of dream.

Our Stories:

Joanne

I had never heard the term ‘crowded isolation’ before coming across tide’s survey about it. But the moment I read the description – this idea of your life being crowded with the responsibility of caring, and people, and things to do, yet at the same time feeling totally alone – it really struck a chord with me.

My mum has vascular dementia. She was diagnosed in 2018, but there had been signs of her memory failing for a while, and when my dad died in 2017, the loss of him and their life together just hit her like a ton of bricks. It was like she crumbled overnight, and that’s when my caring role began. I’m an only child, so the three of us had always been this tight little unit, and although I lived 300 miles away, there was no question of me not spending more time with my mum and doing whatever I could to try and help. As I’m self-employed and work from home, I was lucky enough to be able to do this.

I travelled back and forth between my own home and partner and mum’s to be some company, take her out various places, and keep things ticking over with the house and finances. I eventually ended up in the middle of all her social engagements as well, as her short-term memory gradually got worse.

The feeling of isolation is a strange thing really, as there were plenty of people around. But it sometimes felt like they only ever asked about my mum and didn’t have any idea what my own life was like. We would meet her old friends and acquaintances at the shops and have a chat, and I knew they were looking at us with pity and I think some embarrassment as well, as there was nothing they could really do. Dementia isn’t a thing anyone can fix – something I still struggle with.

I think the times I felt most lonely were in the evenings. Mum liked company to watch TV and we would sit there with Midsomer Murders blaring. There always seemed to be church bells clanging away (what is it with that programme?) and I would look out the window and wonder what had happened to my life. Then I would go to bed in my old room, and it felt like all the years of being my own person had just drifted away or been some kind of dream.

Mum's sister and sister-in-law also did what they could, and I have a great partner and friends who have always been there for me. That's been a great source of comfort, but when you're in the situation and you're 'it', it's still quite overwhelming – especially when something bonkers is going on. It's also difficult for someone who hasn't been in a similar situation to fully understand what it's like. Even talking to other people caring for loved ones with dementia is only partly a relief. They understand some things but every life and every person with dementia is different. I felt like I was disappearing.

My mum is in residential care now, and I finally have the relief of knowing that others can see what her needs are, and that she's being cared for properly. The isolation has lifted. But I miss her terribly and there's this awful guilt and grief that I couldn't be everything she needed. I'm also mourning the fact that I don't have as intimate an understanding of what she's doing, saying or feeling as I did before. I still worry about her, but in a different way.

I was asked what I thought might have helped us. I think some kind of befriending support at diagnosis would have made a big difference. When families are faced with this, there's really no practical or emotional help at all. Having someone who understands what it's like, who can point the way to useful information and services, and maybe just lend an ear at times, would have been brilliant. So many people are out there having to find their way with very little signposting, which I find really sad. I hope at some point I can help someone else who's going through this.

Although I'm not with my mum 24/7 any more I still play an active role in her care and I remain her main advocate. I have a very different relationship with my mum now, and I miss what we had. But all the love is still there, and that won't change. I feel more like her daughter again.

> I found my crowded isolation held me back on so many levels.

Joe

When I was in my caring role, I cared for my mother who had mixed dementia. When in a caring role I went through many issues and emotions. A major one for me was crowded isolation. My take on this is that you tend to feel on the outside looking in, also you feel detached from everybody.

When caring, it is a 24-hour job. Appointments, medication, social services etc. You can get so involved with trying to keep up you feel you're the only person in the world having to cope with this. Every issue or problem can seem a lot bigger than what they are because you're probably trying to deal with too much at once.

I look back to my caring days and think what could I have done better, well I know I could have got support a lot earlier than what I did. That is not to say I was not a good enough carer because I know I was, but the point is that I was offered support in tools to make my caring better to manage in access to support groups and social activities and my own wellbeing - all of which points you to a position to know you're not alone and there are good people waiting to help.

I found my crowded isolation held me back on so many levels. When you fall into this it is difficult to move forward with your responsibilities and that pressure can affect your own wellbeing which is important for you as well as the person being cared for.

Being a carer is a fantastic thing to do for anyone and it's difficult at times, but you have to look after yourself to be the best you can be. There are carers all over the world that experience the same as you. I didn't have to feel I was the only one looking in and that's the same for everybody, and the reason for this is there are many good organisations that can help. That is not to take over but to support you in your caring role.

I reached out to a group called Tide (Together In Dementia Everyday). They have supported me in many ways in caring and continue to do so. I am able to take an active role in carer groups, focus groups and training sessions. You will be meeting other carers who will know how you feel as they have done so. To share your experience can help so much and it's such a positive to get out of it.

Tide will also give you that chance to give you a voice to put your point forward. All of this support has benefited me so much, even giving me encouragement to carry on with my writing which I let slip but now I'm on a course for creative writing. Tide continues to support many carers all over the United Kingdom, and their work is crucial to the support and wellbeing of carers - to them as a person and to their caring role.

This is an account of my caring role. Yours may be different, but if you do identify with my account and get something from it, please look for that support.

All carers do a valuable service. You matter and you count. Please feel supported.

07.

Main Findings

> I didn't sign up for this.

These findings are not Covid-19 or lockdown-specific.
Our 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

08.

Recommendations

> Don’t label or judge me. I’m a human being doing the best I can in a very alien world that doesn’t want to understand.

In order to realise the rights of carers, there needs to be a substantial change in the way carers rights are protected, the way people living with dementia are treated, and in the delivery of accessible, equitable, personalised and high-quality health and social care.

Based on the findings from our work on crowded isolation and loneliness, 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 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

We acknowledge that there is already a growing body of research evidence relating to the experiences of carers, with clear and often repeated recommendations. In order not to re-invent the wheel, we therefore support the implementation of recommendations from previous research; in particular (see Appendix G for detail):

1. Alzheimer's Society (2020) The Fog of Support: An inquiry into the provision of respite care and carers assessments for people affected by dementia
2. Campaign to End Loneliness (2020) Loneliness in Northern Ireland: A Call to Action
3. Carers UK (2015) Alone & Caring: Isolation, Loneliness & the Impact of Caring on Relationships
4. Carers UK Report (2021) Breaks or Breakdown: Carers Week 2021 Report

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 this happen.

> “Dementia is a health care issue. They call it social care, which is unfunded compared to the NHS. This needs root and branch reform. It's critical that dementia care is funded by the government. Nothing less should be tolerated as a point of principle.

These recommendations are from tide. They are not the views of the Northern Ireland Health and Social Care Board or the Big Lottery Fund.

09.

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