

Caring and Coping with Dementia During COVID-19
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THE ALZHEIMER
SOCIETY *of* IRELAND



Caring and Coping with Dementia during COVID-19

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Research Aim

This aim of this research is to explore how the experiences and needs of people with dementia and carers have changed throughout the COVID-19 pandemic and to understand how these needs can be appropriately addressed.

Summary

This report presents the findings of national research undertaken by The Alzheimer Society of Ireland (ASI) between 8th and 26th June 2020, which explored how people with dementia and their carers are coping during COVID-19 and to understand their challenges and needs. This report follows on from a national survey carried out at the start of April 2020, when dementia services ceased operating and COVID-19 restrictions were imposed¹.

This current research consists of online and telephone surveys completed by 126 carers and 15 people with dementia. The carers represent a broad range of experiences, including those caring for varying amounts of time, caring for different family members, different age profiles and those with multiple caring roles. The ASI National Helpline and Dementia Adviser service also contributed to this research. Dementia Advisers work with people with dementia and carers to provide a highly responsive and individualised information and signposting service, and their perspectives provided a crucial insight into the issues affecting carers and people with dementia throughout COVID-19. In addition, The ASI National Helpline, which had 1,039 calls, emails and Live Chat since the initial survey, offered information on the main concerns and challenges reported by these callers since the end March / beginning of April to 12th June 2020.

The research findings of this report clearly demonstrate how the COVID-19 pandemic is shaping the lived experiences of carers and people with dementia. The findings point to their growing vulnerability arising from the cessation of services and supports: According to carers, significant challenges include the cancellation or postponement of medical appointments, a marked decline in dementia symptoms coupled with an increase in responsive behaviours, the loss of routine for the person for whom they care and boredom and anxiety. Those with dementia who took part in surveys echoed many of the concerns and challenges of carers. Additional difficulties include loneliness, social isolation, anxiety and worry and increasing stress resulting from workload leading to burnout and crisis. Our research findings show that living in lockdown has taken an enormous toll on the wellbeing and mental health of carers, a toll that has intensified as COVID-19 restrictions on dementia-specific services have continued despite other lockdown restrictions lifting.

This report illuminates the valuable part played by carers in protecting and supporting an acutely vulnerable cohort during the pandemic. Family carers have cocooned and isolated themselves with their loved ones in order to protect them, coping with an ever increased workload without normal support services and challenging symptoms of dementia, which many had not previously encountered. This research paints a sobering picture of the plight and crisis they now face as a result of their immense efforts. It is essential that their contribution to this pandemic is recognised and

¹ Alzheimer Society of Ireland. 2020. COVID-19: Impact & Need for People living with dementia and Family Carers <https://alzheimer.ie/wp-content/uploads/2020/04/Research-report-Covid19-Final..pdf>

acknowledged, and moreover that their needs and those of the person with dementia are appropriately and adequately addressed from both practical and policy perspectives.

Background and Context

The COVID-19 pandemic has impacted and affected every aspect of Irish society. It poses a significant risk for people living with dementia and their carers. There are an estimated 55,000 people with dementia in Ireland today², with 63% living in our communities and approximately 60,000 people in Ireland are carers of someone with dementia. The care delivered by them accounts for 48% of the overall cost of dementia in Ireland³. There are an estimated 6,000 to 10,000 people living with dementia who live alone in the community⁴. Living with dementia at any time brings everyday challenges for the person and those around them. The challenges from the impact of COVID-19 are making daily life considerably more difficult and exacerbating the vulnerability of this group. Dementia is a complex neurological condition and people living with dementia and their carers have unique needs that require specialised support. A recent report indicates that age is by far the strongest risk factor for dementia and for COVID-19, meaning that many people living with dementia are likely to contract and die from COVID-19⁵.

Even before COVID-19 thousands of people living with dementia were experiencing immense difficulties accessing appropriate dementia services, while carers were struggling with stress, burnout and health challenges. Caring in Ireland is associated with poor health outcomes for the family caregiver⁶. The prevalence of clinical depression for family caregivers of persons with dementia is noted to be three times the Irish national average.

Furthermore, the 2017 Mapping report⁷ illustrated the acute gaps in service provision and the inequitable distribution of dementia services across the country. For people living with dementia and their carers, the COVID-19 pandemic has compounded what were already difficult and precarious circumstances and pushed many carers into further predicament and crisis.

The outbreak of COVID-19 has forced The ASI, the largest dementia specific service provider in Ireland, to temporarily close all its 48 day care centres and suspend vital supports (e.g. Social Clubs, Alzheimer Cafes, Support Groups) Similarly, the Health Service Executive (HSE) run day centres and residential respite also ceased.

On April 1st 2020, in the immediate aftermath of the cessation of dementia services, The ASI carried out research with 150 carers and people with dementia to understand the challenges and concerns

² Pierce, T., O'Shea, E., & Carney, P. 2019. Estimates of the prevalence, incidence and severity of dementia in Ireland. Irish Journal of Psychological Medicine. 36(2):129-37. DOI: <https://doi.org/10.1017/ipm.2018.31>

³ Pierce, M., Cahill, S., and O'Shea, E. (2014). Prevalence and projections of dementia in Ireland, 2011 report prepared for Genio, Ltd.

⁴ Pierce, M., Cahill, S., and O'Shea, E. (2014). Prevalence and projections of dementia in Ireland, 2011 report prepared for Genio, Ltd.

⁵ Hennelly N and Cahill S (2020) The impact of COVID-19 on people living with dementia in Ireland. Report available at LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 2 June 2020.

⁶ Brennan, S., Lawlor, B., Pertl, M.M., O'Sullivan, M., Begley, E. and O'Connell, C., 2017. De-Stress: A study to assess health and well-being of spousal carers of people living with dementia in Ireland. Dublin, Ireland: Alzheimer Society of Ireland.

⁷ Dementia Specific Services in the Community: Mapping Public and Voluntary Services (2017)

<https://www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/Dementia-Specific-Services-in-the-Community-Mapping-Public-and-Voluntary-Services-2017-.pdf>

they faced. Also included were the views of Community Champions from the Dementia: Understand Together initiative and data from The ASI's Helpline, specifically from callers to the Helpline and also from The ASI's Dementia Advisers (DAs). In this initial survey, challenges included the following:

- Pervasive loneliness and social isolation among carers,
- Lack of routine, leading to deterioration of symptoms of dementia and responsive behaviours, such as agitation, wandering and apathy,
- Fear and anxiety among carers and people with dementia,
- Carer stress and fear of being unable to cope, feeling isolated, helpless and overwhelmed by caring workload.

The findings of this initial research were instrumental in informing The ASI's response to the temporary cessation of services and in re-designing a new suite of services to address need during COVID-19, detailed further below. Now, over three months later, we have entered an enhanced Phase 2 of the Irish Government's Roadmap for Reopening Society and Business. However, guidelines and information for the re-opening of services and supports for people with dementia and their families are still unavailable as of the date this report is published. The ASI has again asked people living with dementia, family carers and Dementia Advisers what impact COVID-19 has had. This report presents these findings and provides a snapshot of the challenges being experienced by carers and people with dementia in the immediate aftermath of the COVID-19 pandemic. It illustrates their concerns, anxieties and suggestions regarding supports to meet their needs. The report concludes with a number of recommendations on how we can meet the needs of people with dementia and carers arising from the COVID-19 pandemic in the short to long term. For the purpose of this report, the term 'carers' refers to informal or non-professional carers such as family members, relatives, neighbours and friends.

Methodology

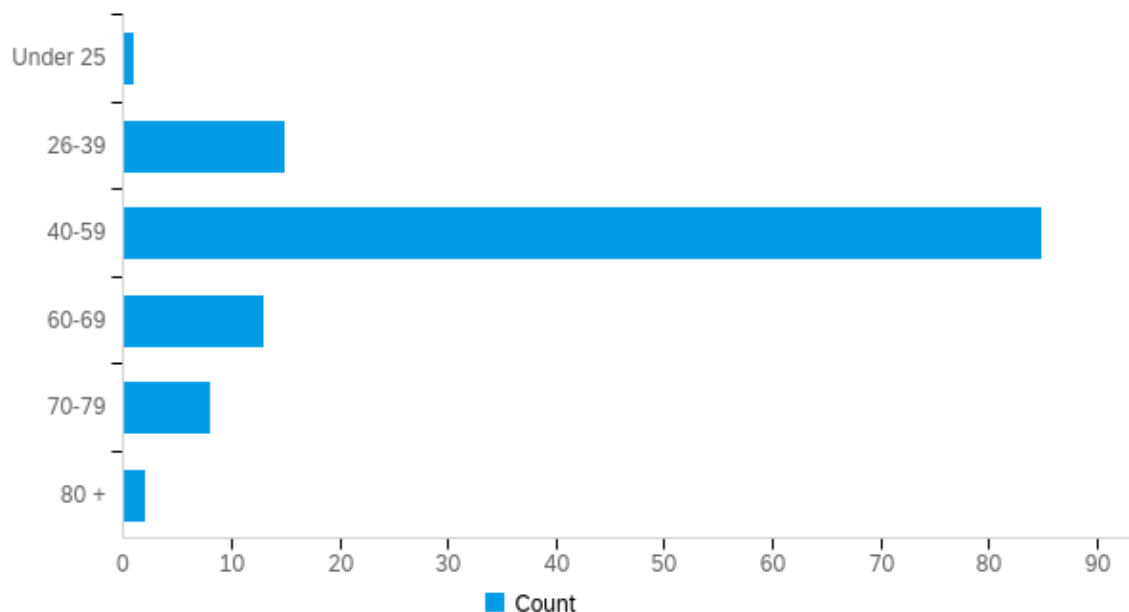
Data was collected via:

- Online and telephone surveys with people living with dementia and family carers from 8th - 12th June 2020.
- A focus group with five Dementia Advisers. In the focus group setting, DAs across Ireland discussed their perceptions of the impact of COVID-19 on families affected by dementia.
- The ASI National Helpline, specifically information about the nature and types of calls to the Helpline.

Key Findings

Profile of Respondents

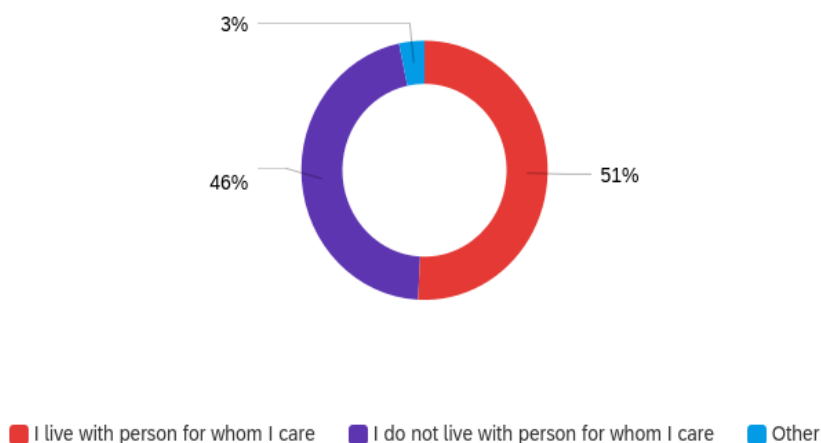
There were 126 carer respondents with the majority, over 80%, between the ages of 40 and 59. Respondents from 27 counties on the island of Ireland took part. 71% live in an urban area (i.e. town or city), 26% live in a rural area (i.e. countryside or small village) while 3% selected 'other' but did not provide additional information.



15 people living with dementia completed the survey representing nine counties in Ireland. Just over one third of participants live in Cork. Almost two-thirds of respondents (60%) describe their local area as being rural, while the other 40% live in urban areas. The average age of respondents was between 66 and 75 years old though four are under 59 years of age.

Caregiving Circumstances

There was a relatively even split in survey respondents' living circumstances. Only family carers were asked this question.



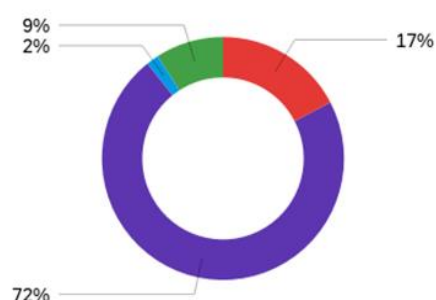
‘Other’ circumstances included temporarily living with the person during COVID-19 or the person with dementia living in a “granny flat” in the garden of the respondent.

Of the callers to the Helpline, the majority, 98%, are carers, with only 2% being people who have dementia or who are concerned about having dementia. Among these cases, 58% live at home with the person with dementia, 13% of callers having a relative with dementia living alone in the community, 6% have a relative in residential care, 6% currently have a relative with dementia in hospital.

Relationship to the Person with Dementia

Most respondents are caring for a parent living with dementia (72%) while 17% are spousal carers.

Respondents that selected ‘other’ are generally grandchildren or nieces/nephews.

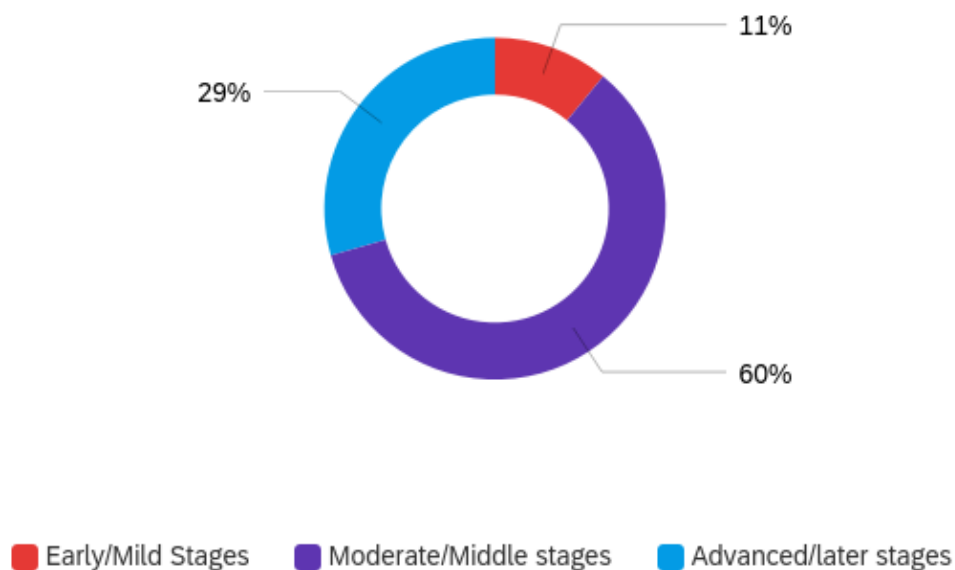


■ Spouse/Partner ■ Son/Daughter/Adult Child ■ Sibling ■ Other

Of the calls to the Helpline, 65% have been from a carer/family member of someone living with dementia and 6% worried about a loved one’s memory/cognitive impairment.

Stage of Dementia (of person being cared for)

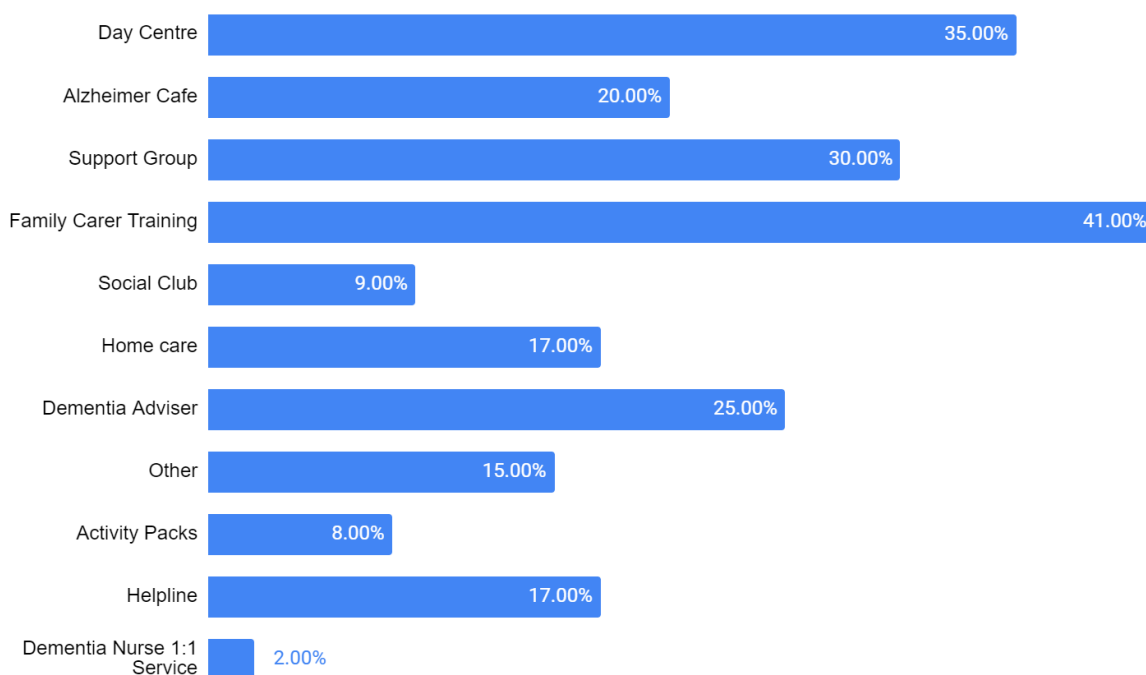
Only family carers were asked this question. Most estimated that the person they are caring for is in the moderate/middle stages of dementia, though just under 30% report caring for a person with advanced dementia.



Among Helpline callers, 24% have been/had a relative diagnosed with dementia less than a year ago, and 34% are 2 years and over and with 41% this was not discussed on the call.

ASI Service Usage

Among carer respondents, family carer training (38%) and day care (35%) were most widely used.

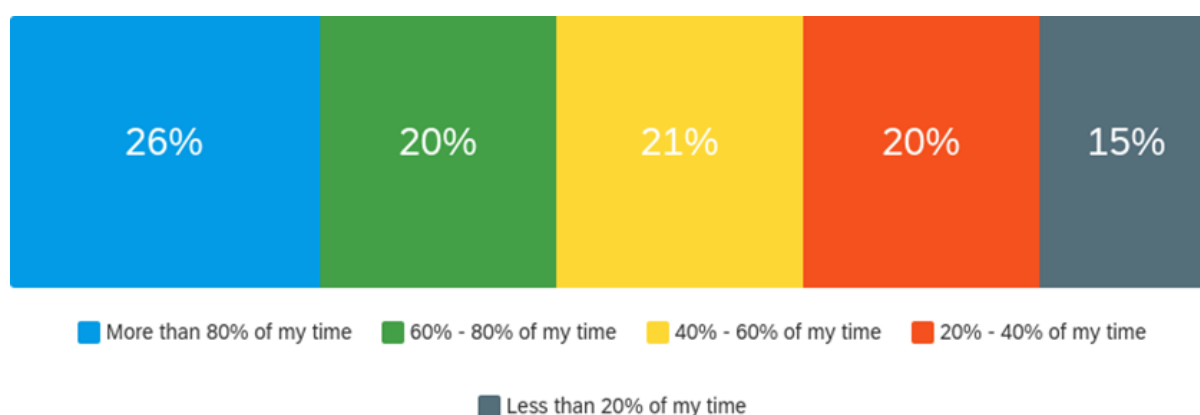


Among respondents with dementia, 70% have a Dementia Adviser while a small number attend support groups or Alzheimer Cafes. Currently, The ASI Dementia Adviser service is continuing remotely while support groups and cafes have been taken online.

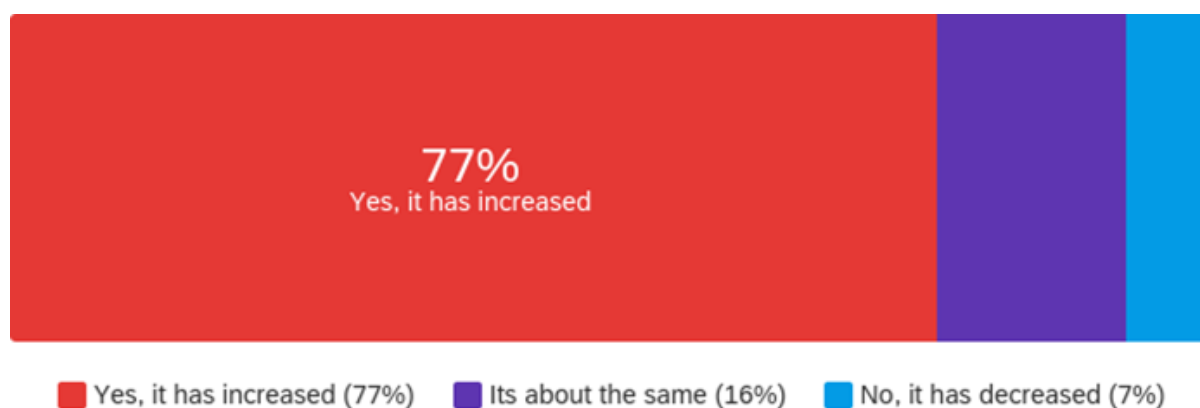
Nearly 40% of Helpline callers are not linked with any ASI services currently, while most survey respondents use or had previously used at least one ASI service.

Time Spent Caring PRIOR to COVID-19

There is a relatively even split among carer respondents in relation to their time spent caring for a person with dementia.



The majority of respondents, 77%, agreed that their caring workload has increased since COVID-19.



Throughout the surveys with carers it is evident that the increased workload presents a challenge,

"I'm tired all the time. Not sleeping well. Worried about Dad all the time. Lack of stimulating ideas and no daycare. A very obvious decline in his health." (daughter caring for parent)

"I find I am doing more for her and this is very tiring, not because of the work but more of the mental challenges that I come up against each day. I find it very draining." (daughter caring for parent)

Impact of COVID-19 on Services

Respondents were asked if the services they normally receive had been impacted by COVID-19. Several participants selected more than one item on the graph below.

Almost 60% of respondents reported that medical appointments for the person with dementia were either cancelled or postponed during COVID-19,

"COVID-19 could not have come at a worse time...Dad could not have any therapy for his speech or hand, appointments were cancelled, and I think because of this he has lost out on valuable time." (daughter caring for parent)

47% experienced cessation of day care services, 42% of support groups and activities for both the carer and person with dementia and 26% experienced closure of respite services,

"Because day care is closed she gets very little stimulation and exercise. Has slowed down considerably." (spousal carer)

"Because we are all at home there is more day-to-day to do and my mum doesn't understand what's going on so she is frustrated. She needs the social interaction of her carer and her friends in day care...Mum has deteriorated without her usual activities, and also hallucinations now, and I guess she won't get a chance to regain lost ground without all the support we got pre lock down with family visits, social gatherings through the Alzheimer's Society, weekly activities. It's all so sad." (daughter caring for parent)

22% of respondents experienced a reduction in home care,

"Our home care was totally withdrawn at the start of Covid when my father was tested for Covid. I cannot physically move my mother alone as she is end-stage Alzheimer's... Words cannot express the stress I experienced trying to look after my sick father with dementia and my mother end-stage Alzheimer's. I felt totally abandoned." (daughter caring for parents)

Many carers expressed concern that the home care worker could bring the risk of COVID-19 into their homes, and for this reason, over a quarter of carers ceased home care. As discussed in the initial report, there is also concern about what constitutes adequate PPE on the part of home care providers:

"We cancelled the home care as the risk was so high with the home carer visiting up to 10 homes in any day, and we were not sure if their PPE was adequate." (spousal carer)

One fifth of family carers (19%) stated that they had difficulty accessing PPE in their role as carers, while 34% believe there is not enough dementia specific information available about COVID-19 in relation to the complexity of dementia.

Indeed, many people with dementia do not understand COVID-19 advice relating to social distancing and visiting restrictions. The cognitively impaired person is also likely to have difficulties remembering safety procedures, such as wearing masks. The wearing of PPE by family members and home care workers can cause confusion and distress among people with dementia. Unfortunately, public messaging and guidelines about COVID-19 have not included dementia at all.

Impact of COVID-19 on services

Of respondents with dementia, nine have been impacted by closure of support groups and activities such as men's sheds and music clubs. Five respondents have had medical/health appointments cancelled or postponed, in some cases there is a delay of an additional year in re-scheduling procedures. One respondent spoke of how she has a medical condition causing her pain but she cannot see her GP. Another respondent is experiencing depression and was advised to stop certain medication due to COVID-19. However, she is now experiencing worsening depression as a result.

Impact of COVID-19: Worries & Concerns

People living with dementia and family carers reported similar worries and concerns in relation to COVID-19:

77% of carers report feeling worried that they will catch COVID-19 and be unable to care for the person with dementia. 67% of respondents with dementia are also very fearful of contracting the virus.

"I had no one to turn to, who could help me with this (caring for her husband). I am on immunosuppressive medication and got very anxious around what if I got sick, as we don't have any family ourselves. What would happen to my husband? If I had to self-isolate that would not be possible as my husband does not understand and would insist on leaving the house. This was very worrying and I couldn't sleep with anxiety."

"This virus will kill me." (man living with dementia)

86% of carers express concern about a decline in the person for whom they are caring. This concern is expressed quite frequently through open-ended comments and questions.

"It (C-19 restrictions) has been detrimental to my mother. She has become more withdrawn, frail, increased confusion and anxiety. Mobility has declined too and incontinence has increased. Marked decline all round." (daughter caring for parent)

"Decline cognitively with loss of daycare supports, with reduction in social contact, change in routine and disconnect with other family members that probably is lost permanently now, even when cocooning ceases." (spousal carer)

"The person's physical health deteriorated hugely during the restrictions, so much that hospitalisation was advised by GP". (son caring for parent)

Callers to The ASI's helpline also echo this sentiment, with concern about progression in the person's symptoms a significant issue since the cessation of services. Callers express confusion, upset and surprise by the rapid and sudden progression of their loved ones' symptoms over recent weeks and months.

As discussed below, The ASI's Dementia Advisers are deeply alarmed about the quickened deterioration in symptoms, as reported to them by family carers. Inherent in carers' experiences is a sense of grief and powerlessness, *"watching the change on a daily basis"*. This is highlighted by the DAs who observe that carers are dealing with grief and loss, in addition to a tremendous workload, and are often alone in dealing with grief as they are often unable to reach out to family members during this time.

Similarly, some respondents living with dementia themselves feel concerned that they are unable to live their life as before and they are losing time.

"I feel my life will never be the same and that I am losing valuable time"

51% of carers report an increase in responsive behaviour in the person with dementia.

Respondents refer to *"increased agitated behaviours"*, *"wandering more, confused more, not sleeping well"* since COVID-19 restriction have been implemented. For some respondents, dementia symptoms have become compounded, *"His sleep pattern which was poor anyway is worse. He is more agitated too"*. Indeed, this concern is widely expressed among callers to The ASI's Helpline who allude to increased challenges including anxiety, not sleeping, paranoia, aggression and hallucinations, all contributing to carer burden. Unsurprisingly, Helpline callers express immense stress and burnout as they struggle to cope with responsive behaviours whilst caring alone during COVID-19 with no 1:1 or personal professional support.

For the person with dementia, understanding COVID-19 guidelines, such as limited visiting, restrictions in movement is particularly challenging,

"Not being able to go to mass has upset Dad, he forgets why and doesn't understand completely. Not having his newspapers initially stressed him. Dad got stressed and confused when my brother left during the pandemic and he couldn't come back as there are no isolation facilities in our house."
(daughter caring for parent)

"Dad is very confused as to why nobody calls by - he feels he has upset his friends and neighbours because they haven't been by for a cuppa and a chat."

Respondents also emphasise the emotional impact of COVID-19 restrictions on the person with dementia. Speaking about her mother, a carer explained, *"It has increased her depression and anxiety, it has somewhat undone all the good work that her medical team set up for her."* Another carer summed up the feelings of her father who has dementia, *"Depressed, agitated, angry, anxiety, unhappy. The list is endless."*

Boredom and anxiety arising from a lack of routine is also common place,

"My dad's anxiety has increased greatly as the routine has changed and doesn't understand why he can't go anywhere". (son caring for parent)

54% of carers report themselves experiencing loneliness and isolation.

"It's worrying. It's lonely. The monotony of continually having to repeat that we can't go shopping, driving etc."

"The loneliness has been so hard and indeed is hard every day with this illness. I feel myself becoming depressed."

Feelings of loneliness and isolation are also echoed by callers to the Helpline, and identified by the Dementia Advisers as consistent difficulties for family carers. Many Helpline callers report that simply chatting to someone on the Helpline has been helpful in this regard. The ASI's Dementia Nurse Service, which commenced at the end of April 2020 in response to COVID-19, offers a free call-back service which offers people with dementia and carers the opportunity to book a 1:1 phone session with a Dementia Nurse to discuss specific issues that may be arising for them. Of all the calls coming through for the Dementia Nurses, carer stress arose in over 40% of calls along with increased isolation, loneliness and struggling to cope day-to-day. Family carers have fears about the effects their own health decline will have on their ability to continue and sustain their carer role. They have had to respond immediately to this crisis, and many feel they have lacked guidance and adequate PPE. The COVID-19 pandemic and the resulting lockdown are likely to have contributed to an increase in carer burden and to carer ill-health.

58% of respondents with dementia also report feeling lonely and isolated during COVID-19 as they contend with suspended services and cocooning.

"I miss seeing my family and I miss socialising. It's hard not to let it get on top of you" (person living with dementia)

"It (COVID-19) has taken away my freedom to travel and socialise"

"I feel trapped"

61% of family carers are concerned about a decline in their own mental health.

A male carer for his mother mentioned, *"I cope well, but I drink (alcohol) to cope with my mother's dementia and all the workload."*

"To keep my parents safe I have moved in with them to keep them safe and minimise carers' sleeping over. This has taken a toll on my marriage, family life, and physical and mental wellbeing." (daughter caring for parent)

"Locked down with no idea as to when I can have a day off, no day care, no respite and no idea as to when it will resume! Feel alone as I feel as carers we are forgotten! Very tired and stressed!" (female carer)

Indeed, in the focus group with DAs, participants described carers as “*in crisis*”, and receiving a marked increase in calls from carers experiencing suicidal thoughts. DAs allude to carers experiencing increased “*depression*”, “*loneliness*”, feelings of “*abandonment*”, and recognise that this will have a direct impact on the person with dementia and diminish carers’ capacity to continue providing care.

Similarly, 75% of respondents with dementia are also concerned about a decline in their mental health.

“I wouldn't really go anywhere far on my own at the moment. I have been struggling with depression and the evenings are lonely and difficult. I watch television but there's only so much you can watch.”

36% of family carers are concerned about a decline in their own physical health. A number of respondents explained they have their own health difficulties, which have been exacerbated by the pressure and stress of their caring role, as also suggested above.

67% of respondents with dementia are concerned about their physical health. Many have felt fearful of going for walks while another remarked that he forgets about social distancing so he avoids going out. For others existing health problems are compounded: “*It's hard not to let it get on top of you. Can't see GP and suffering with a condition and need to see them*”.

41% are worried about when normal dementia services will re-start. This is particularly concerning for carers who are also in employment,

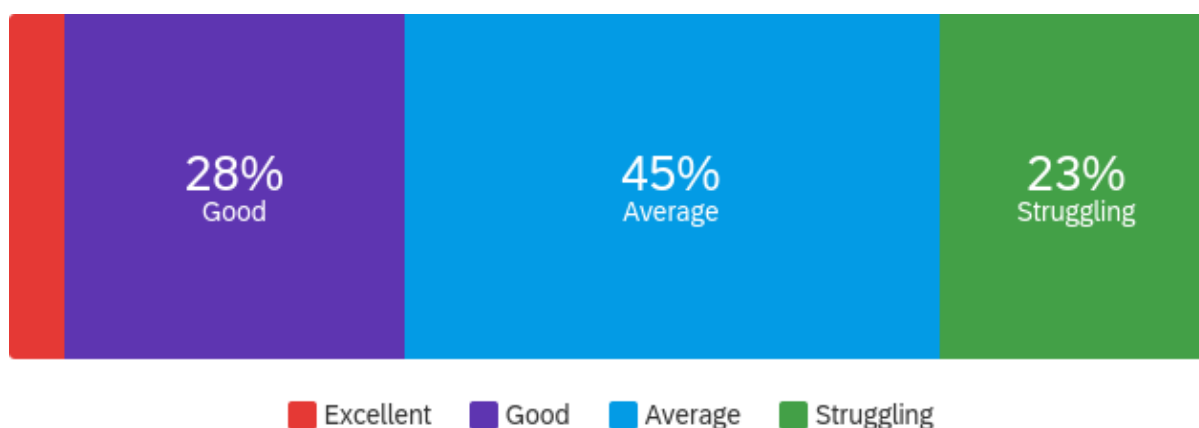
“I will be going back to work at the end of June and this frightens me as I won't be available to (my mother).” (daughter caring for parent)

The lack of certainty around re-opening of services is a source of ongoing frustration and angst as it means there is no end in sight to carers’ stress and workload, thereby leading to feelings of desperation and hopelessness, discussed below.

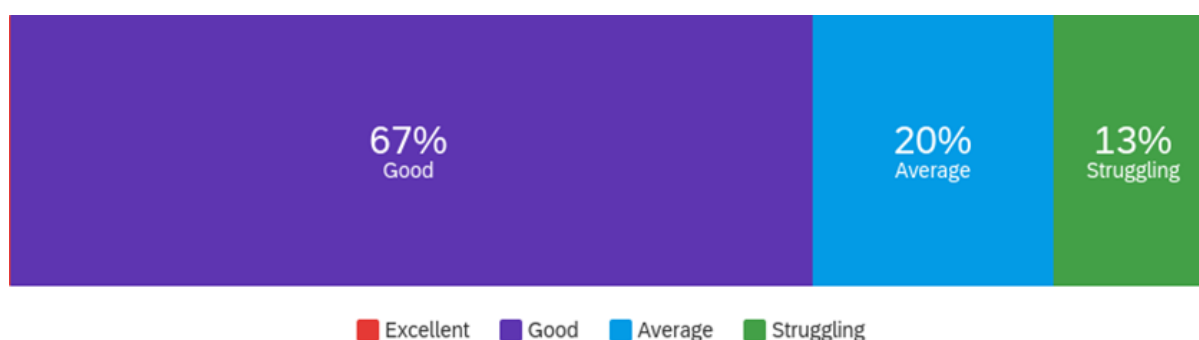
50% of respondents with dementia worry about when services will re-open mainly because they miss socialising with friends. Friendships, social interaction and social activities emerge as important to respondents with dementia. COVID-19 restrictions and advice on social distancing present as a significant barrier to social engagement.

Coping During COVID-19

Respondents were asked to rate how they feel they are coping during COVID-19. Almost one quarter of family carers (23%) consider themselves to be ‘struggling’. Only one third of respondents felt they were coping well (i.e. good or excellent). It is interesting and noteworthy that many of the 45% of respondents who describe their coping as ‘average’ also describe experiencing immense difficulties, anxiety, stress and increasing mental health challenges. It may well be that the 23% describing themselves as ‘struggling’, are already in crisis and at the point of burnout, and indeed the challenges outlined further below, point to deepening crisis and exhaustion among carers.



This is a contrast to respondents with dementia. 67% feel they are coping well and just 13% (n=2) feel they are struggling. Again however, participants who indicated that they are coping well also spoke of finding COVID-19 very difficult and feeling lonely and isolated.



Greatest Challenges: COVID-19 and Caring

Respondents were asked what they perceive as the greatest challenges they encounter during COVID-19:

1. Anxiety

Respondents cited anxiety as one of their greatest challenges and it appears that anxiety is pervasive, relating to the person with dementia being unable to follow COVID-19 guidelines around social distancing and hand-washing, contracting Coronavirus, juggling caring roles, dealing with practical challenges and planning. Many family carers are experiencing constant anxiety. Respondents also describe the stress of a “relentless” workload, such as, “*Stress of constant planning, how to get medication, how to get shopping, how to get to the post office.*”

Anxiety is also an issue for carers who have to return to employment, and indeed, the ASI’s Dementia Advisers recognise that some carers are fearful of how the person with dementia will cope in this event. Both DAs and carers explained that while they had additional support from family members and

friends at the outset of the pandemic, this support has in many cases subsided as family members step back, and the care burden falls to the primary carer who may also have employment responsibilities.

As outlined above, respondents' caring role varies in terms of time commitment. During COVID-19 some carers were unable to spend significant time caring for the person with dementia, as another family member may have moved in to provide care. Nonetheless, despite not living with the person with dementia during COVID-19, many of these respondents express feelings of underlying anxiety and guilt,

"I have not been able to visit my elderly parents or help out in any practical way my siblings who are caring for my parents. This is very distressing for me." (son caring for parents)

For some carers, this is a source of frustration and concern, which may arise from feelings of powerlessness and helplessness:

"Mentally it's more challenging to me as I am not present when they need me and phone conversations about how to change a TV channel are increasing. Little things that were easy for my Mam are now difficult." (daughter caring for parent)

It is particularly distressing for family members who under normal circumstances play a part in caring for the person but cannot spend time with the person and are also aware of a decline in the person's dementia symptoms, *"Not being there every day they are declining so much is the worst thing."*

Some carers express distress and upset that the person with dementia is deteriorating at a faster pace and the impact this is having, such as, *"fear that I will not be able to hold a normal conversation again."*

Financial strain presents as another source of anxiety, and some carers worry about the financial cost of caring, particularly associated with home care.

Respondents with dementia are also experiencing a good deal of fear and anxiety. They worry not only about getting the virus themselves, but are also fearful on behalf of their families. Even though many are feeling lonely, some are scared of meeting people.

2. Isolation and Loneliness

In the initial survey with carers at the outset of COVID-19, isolation and loneliness emerged as significant for carers. This has not changed and as the country emerges from COVID-19 restrictions, isolation and loneliness present as pressing underlying challenges. The Dementia Advisers describe carer loneliness and isolation as pervasive, and while these difficulties were present before COVID-19, they are now more acute.

Carers talked about how COVID-19 has compounded their sense of isolation:

"In the earlier days of lockdown, I was very depressed. It struck me very forcibly just how isolated my life had become...I suppose I never allowed myself to think about how small my world is. Of course I'm happy that Covid is coming to an end, but a small part of me resents the fact that the majority of

people will go back to what they call 'normal' and we (carers) will stay as we are, in a never ending lockdown." (daughter caring for parent)

Loneliness and isolation was the most frequently cited challenge by respondents with dementia. They spoke of how they were missing their families, their friends, attending activities in the local community and feeling confined to their house.

"I feel confined and fed up, I can't see my friends the way I did before" (person living with dementia)

"...I'm still locked in it [COVID-19]. I wouldn't really go anywhere far on my own at the moment. I have been struggling with depression and the evenings are lonely and difficult. I watch television but there's only so much you can watch" (person living with dementia)

"It [COVID-19] has kept me isolated from my rainbow family of support" (person living with dementia)

3. Boredom and Lack of Routine

Carer respondents frequently refer to feelings of boredom, both on their own part and of the person with dementia. The unexpected and sudden cessation of dementia services and supports meant that carers were unable to plan and were left struggling to cope without support. A lack of routine was highlighted as an ongoing challenge and respondents expressed frustration that they are unable to go places, and trying to engage with and stimulate the person with dementia can be onerous and tiring. Respondents describe having to constantly explain the restrictions to the person with dementia, and the frustration this brings, particularly as the person wishes to visit family and friends and cannot understand why people have stopped visiting.

It is known that some responsive behaviours, such as agitation, apathy, depression, wandering can be precipitated by boredom, lack of routine and the absence of multisensory stimulation. As indicated, respondents point to a marked rise in responsive behaviours as a consequence.

For some respondents with dementia, COVID-19 restrictions have greatly disrupted their daily life, *"I had to leave Dublin and live with my sister because I wasn't eating and I couldn't manage my tablets. I was very stressed about everything."*

4. Lack of Support

A lack of support and work overload are also constant dilemmas. The persistent care workload means that many carers cannot leave the person with dementia and have little or no time to themselves, and no opportunity to take a break from caring. Respondents alluded to feeling *"overwhelmed"* and experiencing *"low mood"*. Some described being completely alone, *"I have no one to help me"* along with a deepening sense of mental and physical exhaustion.

For some carers who had managed to secure formal supports in advance of the cessation of services, the absence of support is particularly frustrating and disappointing,

"We were just about to place my mother-in-law in a day care service. This would have allowed 6 hours every second week when we could attend to other family / home needs ... It would also mean that for

those 6 hours, we could have time to let go of the responsibility we (my husband and I) carry in caring.”
(female caring for relative)

Interestingly, a number of carers observed that the person with dementia was somewhat oblivious to the disruption caused by COVID-19 and was not experiencing stress or worry. In these cases the carer made considerable effort to ensure the person was occupied and busy. It seems the carer was absorbing the stress and seeking to protect the person with dementia from experiencing anxiety or worry.

Multiple Caring Roles

Some respondents are caring for several family members, such as one parent having dementia, while another has a chronic disease, or also caring for a child with a disability. Many carers also have young children and employment responsibilities. Family carers talk about feeling guilty about *“not being able to attend properly to other needs in the household”* and the feeling that they are not doing enough.

The presence of COVID-19 does not erase family dynamics and several carers refer to family members’ denial that the parent has dementia and/or the pressure of taking on the lion’s share of caring, either because of other family members’ refusal to help or because of isolation and cocooning requirements. Callers to the Helpline also allude to family conflict as a source of stress.

A Deepening Crisis

Of concern is the sense of growing anxiety and fear among many family carers and increasing burnout and fatigue, which presents a scenario of crises for many families. Several carers expressed worry that the person with dementia will have to enter long-term care because they are unable to cope any longer. In addition, the high mortality rate in nursing homes may bring worry and unease about nursing home care for their loved ones. Respondents describe feelings of despair, hopelessness and desperation, and uncertainty about how they will continue to cope. Words such as *“devastation”, “torturous”, “exhausting”, “depressing”, “incredibly stressful”* are used to describe the impact of COVID-19 on their daily lives.

The Dementia Advisers make the point that the lifting of restrictions has not eased circumstances for carers. Many carers fear a second wave of COVID-19 and are therefore reluctant to engage more with family and friends and some feel nervous about accepting visitors into their homes. Accessing services and services, including both dementia-specific and medical appointments has now become more difficult. At the time of preparing this report, there was no guidance available on the re-opening of dementia services.

The precarious circumstances of many carers was summed up by one DA:

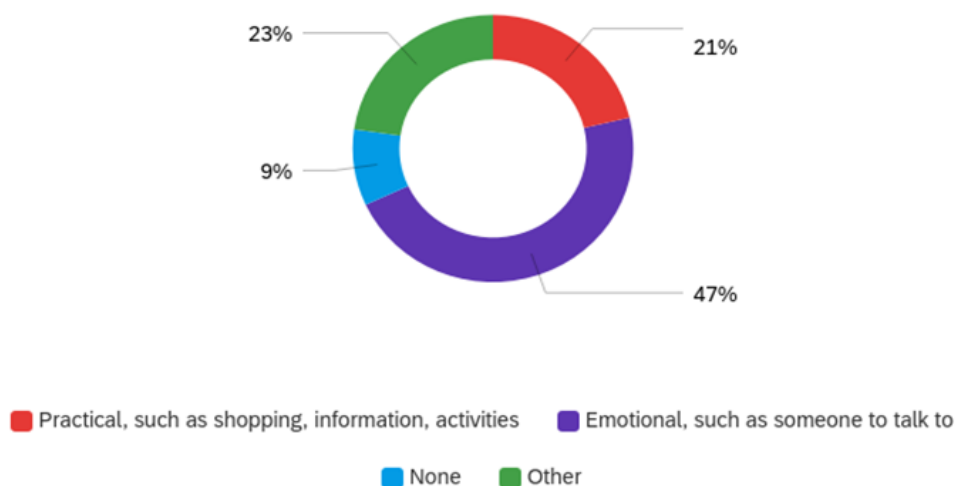
“Carers are at breaking point. With no idea of when services will be back, carers can’t see a light at the end of the tunnel and they really need one. Carers are suffering with depression and no services, experiencing a huge loss of identity, purpose, and role. No social support.”

Also foreseen by DAs is the long-term impact for carers on mental and physical health. Many people with dementia are acutely vulnerable as their carers have reached a crisis point and their ability to provide care is diminished, which may lead to safeguarding issues.

Carer Needs

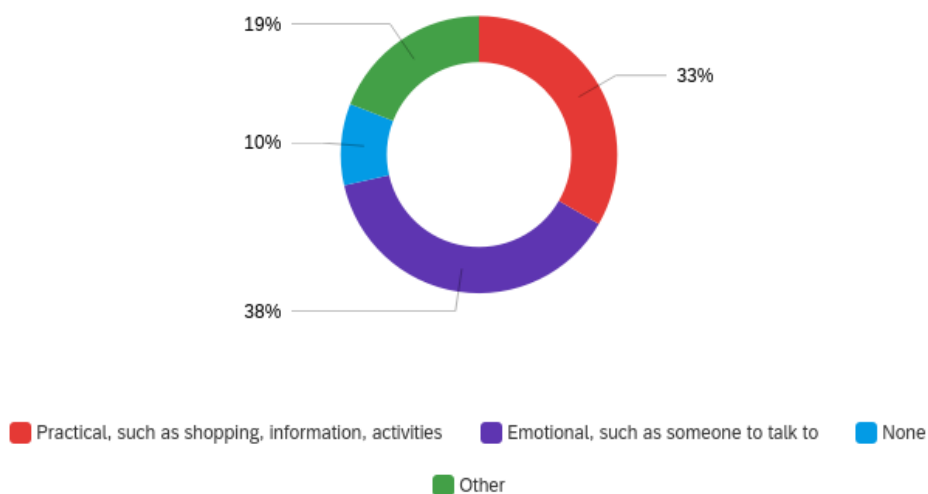
When asked what kind of support they need as carers, 47% of respondents reported needing emotional support, such as someone to talk to, while 21% are in need of practical support, such as help with shopping and information. For the 23% who mention 'other', this refers largely to resumption of dementia service and supports, including respite and day care.

A small number of respondents (9%) reported needing no carer supports at this time. This is a sharp contrast to four months ago when 22% of carer respondents reported needing no supports.



Needs of People Living with Dementia

Just 10% of respondents living with dementia report needing no support while almost three quarters need either emotional or practical support or both. Again, this is a clear contrast to four months ago when almost 27% reported needing no support. Compared to the previous ASI report, emotional support is now needed much more. Four respondents selected 'other' and responses include LGBT+ peer support, opportunities for socialising in a safe way, and more information from The ASI through simple newsletters.



Dementia Adviser Perspectives: Supports & services

While the DAs note the above challenges are significant for carers and people with dementia, they also emphasise a chronic lack of services and supports, including both health and social care services, as significant challenges. The DAs made the following observations in relation to services:

- Of concern is that people are continuing to be diagnosed with dementia during COVID-19 and are now met with no services or supports. DAs are noticing a notable rise of younger people with dementia, including frontotemporal and also lewy body, who may have children and responsibilities such as mortgages. Such cases present a different and very challenging set of difficulties, and there is minimal support for this cohort at present.
- As mentioned above, family carers are seeing a marked decline in the person with dementia as a result of COVID-19 restrictions. DAs acknowledge that this is exacerbated by the fact that medical reviews and interventions are currently unavailable.
- As dementia is now progressing more rapidly for some people, it is alarming that no medical reviews or interventions are currently available. Many reviews that do happen are taking place by phone, and this is largely inappropriate for cognitively impaired people. DAs mentioned that even their own service is not as impactful or effective via phone or video call and are keen to resume face to face appointments.
- Approximately half of phone calls to DAs are from carers struggling to contact health care professionals in order to access services. While there were service gaps pre-Covid and DAs would attempt to address these by linking carers in with specific health care providers and supporting carers to arrange appointments, this is no longer feasible, and is a source of immense anxiety for carers.

- There is a notable increase in family carers turning to unregulated home care out of desperation, and this is a cause for concern as it may not be appropriate or safe care for the person with dementia.
- Some families who previously did not utilise dementia services are now seeking these services and supports, and as a result, DAs predict a marked increase in demand for dementia support once services resume.

Acknowledging that *“carer concerns prior to lockdown are now quadrupled”*, DAs are of the view that home care should be immediately available to those unable to access day care, and that therapeutic services including counselling should be made available to carers.

New Services in COVID-19

As most ASI services have been suspended due to COVID-19, a new suite of remote services was developed to complement the existing services that are still operating. These new services were developed with the input of people living with dementia, family carers, ASI staff, and other stakeholders.. Our initial COVID-19 survey and report detailing the challenges experienced by people with dementia and family carers and exploring what supports they needed, informed development of these new services.

Each new service provided by The ASI is being evaluated to ensure that all services meet the needs of people with dementia and family carers:

- **Online Carer Support Group:** This online support group is a dedicated space for family carers to find information and resources, get support and guidance, and to talk and share openly with other family carers. It is intended to mirror face-to-face support groups that are now suspended.
- **Dementia Nurse 1:1 Service:** This is a free call-back service which offers people with dementia and family carers the opportunity to book a 1:1 session with a Dementia Nurse to discuss specific issues that may be arising for them.
- **Alternative Activity Therapy:** This is a service for people living with dementia and their family carers who availed of day care prior to COVID-19. The ASI are providing Social calls and Activity Engagement Calls (with Activity packs) on a weekly or biweekly basis.
- **Virtual Alzheimer Cafe:** This service is intended to mirror previous face-to-face Alzheimer Cafes. They are hosted weekly via Zoom. Each cafe includes a talk from a speaker (e.g. lawyer, dementia adviser) and question and answer session.
- **In-home respite:** Currently being piloted, this offers enhanced and dementia-specific home care.

23% of respondents reported that they have started using new services during COVID-19, and these include the above ASI services. Non-ASI services used by respondents include:

- ALONE Befriending Service
- Meals on Wheels (for their loved one with dementia)

- Engaging Dementia Virtual Cafes
- Shopping deliveries from local community groups
- Video-call activities such as Sing-a-longs and the Engaging Dementia Virtual Alzheimer Cafe
- Joining Facebook Groups for support and information

Need for Service Re-Commencement

When asked if The ASI should provide additional service to better support family carers, 40% of respondents agreed. This mainly related to re-opening and resuming services, particularly day care. This is not surprising considering that 40% of carer respondents struggled to access services for their loved one with dementia even prior to COVID-19, while another 10% were diagnosed prior to COVID-19 and has only begun engaging with services. The need to re-open day care and the impact of cessation of day care on the person with dementia and the carer is a strong theme throughout the research. Carers talk about the person missing the interaction with other clients and staff, missing their friends in day care and the routine and stimulation it brings. Many carers attribute a decline in the person's symptoms to the lack of stimulation, routine and interaction of day care and other activities.

Some carer responses called for services that The ASI has already recently launched such as Virtual Alzheimer Cafes and Online Carer Support Groups. The ASI is piloting in-home respite for people who previously used our day centres and there appears to be a good deal of demand for this:

“In-home person to sit with dad while Mam gets some needed time out. My dad is so well cared for he is so calm and wonderfully humble in his illness. It's my Mam that needs the help, she's 76 and 24 hours a day minding him. We pay for some private care but it's not enough.” (female, father with dementia)

Other suggestions include,

- Counselling for the family carer, also suggested by DAs
- Group video calls with people who used day centre so they can see each other
- *A moderated message board to ask questions, compare notes, get tips or just as a sounding board amongst others who are coming from similar situations (this is currently part of The ASI's Online Carer Support Group).*

Some respondents feel they need more information from The ASI and assistance in navigating services. This was mainly related to non-ASI services and initiatives such as the Fair Deal Scheme or HSE protocols.

Key Recommendations

Arising from this research, the following are practical and policy recommendations on addressing the needs of people living with dementia and family carers resulting from the COVID-19 crisis in the short to long term:

1. Guidelines for reopening of services and supports for people with dementia and carer need to be addressed as a matter of urgency. In particular, the recommencement of day care services needs to be examined and how this can be resumed in a way that is safe whilst meeting needs. The ASI has submitted a proposal to the HSE detailed how safe re-opening can occur. The ASI's recent evaluation of day care services (to be published) draws attention to the wide range of benefits of day care to people with dementia and makes recommendations for quality improvement and innovation in dementia-specific day care that can potentially inform guidance for resumption of this service.
2. Dementia has not been included specifically in data collection relating to COVID-19 mortality or public messaging. Public policy discussions relating to COVID-19 should include people living with dementia who struggle to adhere to public health guidelines and have been adversely affected by the cessation of services and supports. The lack of emphasis placed on the complex needs of those living with dementia, whether in the community or in residential settings, should be addressed. Dementia as a disease should be considered not just by association or implication as it is a serious disease in its own right. It should be considered alongside other chronic diseases in planning and managing COVID-19 guidelines and service re-opening.
3. Public policy should focus on supporting family carers who have shouldered a disproportionate burden during this global pandemic. Supports for carers need to be put in place immediately to address both the short and long-term needs of carers arising from COVID-19. This should include crisis prevention care, and therapeutic services including counselling should be made available to address the rise in mental health challenges.
4. Planning and investment is essential to meet an increase in service demand as many family carers who were closed to services before COVID-19 are now seeking these services. Moreover, demand and need from those previously using services will increase significantly. Prior to COVID-19, The ASI has maintained that no county in Ireland has a minimum standard of services to meet the needs of both carers and those with dementia. Therefore, investment in and planning of dementia services must be prioritised immediately. The National Dementia Strategy should be fully implemented, and there needs to be strong commitment from Government to investment in its implementation.
5. Before COVID-19 there was a serious shortage of home care for people with dementia. Enhanced in-home support that caters appropriately for people with dementia should be implemented immediately with emphasis on the specific needs of the person, rather than simply on task-driven care. Moreover, the statutory home care scheme should be piloted and developed without further delay.
6. Carers and people with dementia require additional support navigating services and there is a clear role for Dementia Key Workers in this regard in terms of case management and coordination of care, particularly for those family carers who are in crisis.

Concluding Remarks

Since the COVID-19 pandemic, the rest of society has experienced what people with dementia and their carers had already been experiencing on a daily basis; isolation, fear, anxiety, physical and social distancing for many including often from family and friends. Systemic discrimination and stigma can bring additional isolation, and lack of support leaves many carers with no option to take time out from their sustained workload and full-time role of caring.

COVID-19 has not caused this plight, rather it has brought into sharp focus how people with dementia and their carers are routinely neglected and overlooked. Indeed, the nursing homes sector has been especially affected by the crisis, with nursing home residents comprising more than half of all deaths attributed to the disease here. We know that 70% of all nursing home residents have dementia, making them a particularly vulnerable group.

In the community, while many family carers were struggling to cope prior to COVID-19, this crisis has amplified their difficulties and turned everyday caring into a daily struggle. In our initial COVID-19 Survey published in early April, some carers expressed the fear that they would be forgotten in the midst of the crisis; this fear has been realised as they and those they care for have been rendered invisible throughout this pandemic. The voice of the person with dementia and their carers and the visibility of the disease needs to be strengthened, and their wishes should be reflected in the treatment and care they receive.

There may be an upside to COVID-19; it has made society at large more aware of the most vulnerable and the plight of older people is receiving long overdue attention. It is clear that this pandemic has changed the world, and now we must respond by listening and responding to their needs in ways that are meaningful, person-centred and effective. Another upside to COVID-19 is that more online and virtual support is being offered, which can support people in remote or rural areas in ways that are creative and innovative. At the onset of COVID-19, The ASI immediately responded by redesigning many activities and services, and these efforts will continue over the coming weeks and months, and into the post-Covid era. However, this alone will not be sufficient to address the new and increased needs faced by those living with dementia. Face to face services must be re-opened, re-imagined and re-developed in order to respond to the pre-Covid and post-Covid challenges for those living with dementia and their family carers. Their right to care and the humane provision of adequate and appropriate care must be paramount now.

Acknowledgements

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