

Caring and Coping with Dementia During COVID-19:

Experiences of People living with Dementia and Family Carers



THE ALZHEIMER
SOCIETY *of* IRELAND

INTERACTION CHANGE
FEED CARE SOCI
ISOLATION
BREAK CO
TIME WORK
PRESSURE SUPPO
ANXIETY

Contents

RESEARCH AIM	1
SUMMARY	2
BACKGROUND AND CONTEXT	4
METHODOLOGY	5
FINDINGS	6
Profile of respondents	6
Services and Supports	10
Concerns during COVID-19	11
Key Challenges	13
Exploring the Ongoing Impact of COVID-19	14
Dementia Adviser and Staff Perspective	20
The Impact of COVID-19 on People Living with Dementia (Perspectives of DAs, ASI Staff and Family Carers)	24
Perspectives of People Living with Dementia	30
Coping During COVID-19	32
Understanding Distress	34
Supports Needed	39
KEY FINDINGS	43
KEY RECOMMENDATIONS	44
CONCLUDING OBSERVATIONS	46
Acknowledgements	48

DAND DAD

SAFE

DAD

HOME

ILLY DAY

PEOPLE

LIFE

BREAK

WODDY

RESEARCH AIM

The aim of this research is to explore the impact of COVID-19 on people living with dementia and their families one year on from the onset of the COVID-19 pandemic and the cessation of dementia services. We aim to explore the experiences and needs of this cohort, and how, if at all, these have changed over the course of the Pandemic.

SUMMARY

This report presents the findings of national research undertaken by The Alzheimer Society of Ireland (ASI) between February and March 2021, which explored how people with dementia and their family carers are coping during COVID-19 and their challenges and needs, twelve months after the implementation of national restrictions and service closures. This report builds on a national survey carried out in April 2020¹, when dementia services initially ceased operating and a further report in July 2020² as services remained closed. This report marks one year since the widespread closure of dementia services and supports.

This current research consists of online and telephone surveys completed by 240 family carers and 17 people with dementia. The family 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's national Dementia Adviser service and Day Care at Home Service also contributed to this research in the form of focus groups. Dementia Advisers work with people with dementia and family carers to provide a highly responsive and individualised information and signposting service. Staff involved in Day Care at Home work directly with people living with dementia to provide activity-based care in the absence of Day Care Centres. ASI Staff have provided a crucial insight into the issues affecting carers and people with dementia throughout COVID-19.

- 1 The Alzheimer Society of Ireland, April 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>
- 2 The Alzheimer Society of Ireland, July 2020, Caring and Coping with Dementia During COVID-19 <https://alzheimer.ie/wp-content/uploads/2020/07/ASI-Follow-Up-Covid-Report-Final.pdf>

These research findings show the profound effects of COVID-19 public health measures and closures of vital services on the lives of people affected by dementia. The findings point to the devastating impact of the absence of services providing cognitive stimulation and social engagement, and the resulting accelerated decline of symptoms among people with dementia. Despair, loneliness, apathy, helplessness, grief and anger are experienced by family carers as they grapple with overbearing workloads and burn-out. Our research indicates that many family carers continue to remain at breaking point and their mental and physical health is suffering while other relationships and priorities are also under strain.

This report sheds light on the invaluable and courageous role played by family carers across communities in Ireland as they strive to protect and support vulnerable family members throughout this pandemic. Family carers have made enormous sacrifices and have isolated themselves in order to protect those for whom they care. This research presents the sobering reality of the plight and crisis they now face. Their contribution and role throughout this pandemic should be recognised, and their needs and the needs of those they support should be urgently and appropriately addressed through practical and policy measures. This 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.

BACKGROUND AND CONTEXT

Living with dementia at any time brings everyday challenges for the person and those around them. COVID-19 has made life considerably more difficult and exacerbated 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. Accessing appropriate care and support services is key to the well-being of people living with dementia and those who care for them. COVID-19 has caused sudden cessation or reduction in these vital services and is resulting in prolonged hardship and ill-health for many.

Even prior to the COVID-19 pandemic, significant gaps in services and inequitable distribution of dementia service provision had been highlighted³. Indeed, The ASI has advocated for at least a minimum level of basic service provision across communities to meet growing need as thousands of people living with dementia were struggling to access appropriate dementia services, while family carers were struggling with stress and caregiver workload. The prevalence of clinical depression for family caregivers of persons with dementia is noted to be three times the Irish national average⁴.

The COVID-19 pandemic led The ASI, the largest dementia-specific service provider in Ireland, to suspend vital services, including its 48 Day Care Centres, Social Clubs, Alzheimer Cafes and Support Groups. Similarly, Health Service Executive (HSE) day centres and residential respite also ceased in March 2020. On April 1st 2020, in the immediate aftermath of the cessation of dementia services, The ASI carried out national research with family carers and people with dementia to understand the challenges and concerns they encountered, also including the views of ASI service providers such as Dementia Advisers (DAs) and the National Helpline. This research pointed to pervasive loneliness and social isolation among carers and a lack of routine for people with dementia leading to deterioration of symptoms and responsive behaviours, such as agitation, wandering and apathy. Also noted were fear and anxiety among carers and people with dementia, as well as carer stress and feeling overwhelmed by the caring workload.

3 Dementia Specific Services in the Community: Mapping Public and Voluntary Services (2018) The Alzheimer Society of Ireland and the National Dementia Office in the Health Service Executive.

4 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.

In July 2020, further research was carried out to understand how people living with dementia and family carers were coping as services remained closed and national restrictions were implemented. This second research report *Caring and Coping with Dementia During COVID-19* further highlighted the crisis aftermath of life in lockdown which has taken an enormous toll on people's lives resulting in family carers facing crisis with extra workloads, constant anxiety and exhaustion. The findings of this research were instrumental in informing The ASI's response in the immediate aftermath of the cessation of services and in re-designing a new suite of services to address need during COVID-19.

Now one year after the cessation of services due to COVID-19, this follow-up research builds on our understanding of how those affected by dementia continue to care and cope amid deficient and sparse service provision. The ASI has again asked people living with dementia, family carers and ASI service providers about the impact of COVID-19, how it continues to shape their lives. This research report brings to life their concerns, anxieties and everyday challenges.

METHODOLOGY

Data was collected via,

- Telephone and online surveys with people living with dementia and family carers from 16th February – 29th March 2021.
- A focus group with nine Dementia Advisers and six front-line service managers. In the focus group setting, those working in communities across Ireland discussed their perceptions of the impact of COVID-19 on families affected by dementia.

FINDINGS

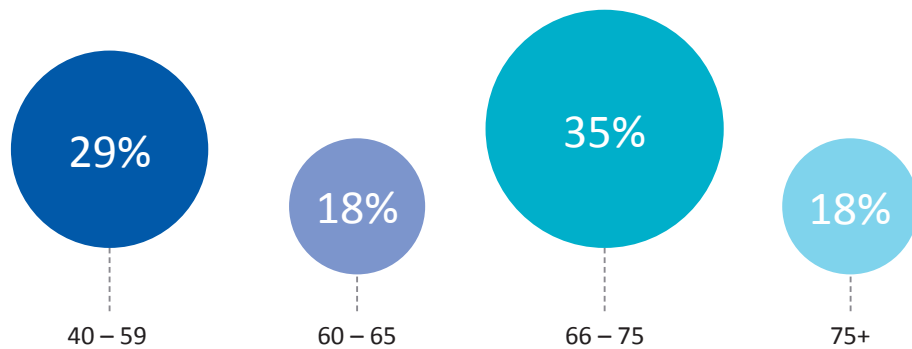
Profile of Respondents

17 people living with dementia and
240 family carers took part in this research.

People living with dementia

A quarter of respondents with dementia live alone while others live with at least one family member (generally a spouse). Almost half live in a 'village/small town' while others live in 'rural' areas (18%) or 'large towns/cities' such as Dublin and Cork. Five respondents live in Dublin, four in Cork and two in Tipperary. The counties of Fermanagh, Kilkenny, Roscommon, Sligo, and Wicklow were represented by one respondent from each.

FIGURE 1:
Age range of respondents with dementia

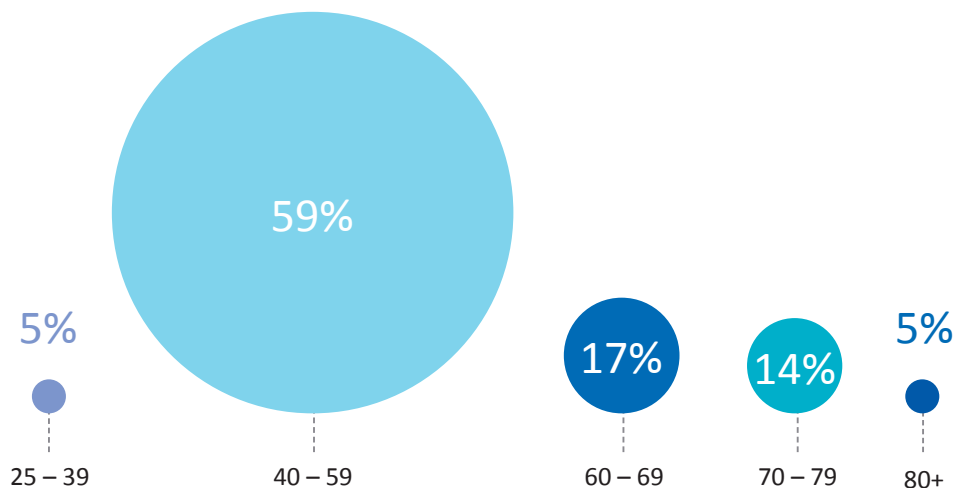


Family Carers

The largest group of carer respondents (59%) were between the ages of 40-59 years old. No respondents were under the age of 25 years old. Almost 20% were over 70 years of age.

The majority of respondents live in a large town or city (60%), mainly Dublin. There was at least one respondent from every county in the Republic of Ireland with the exception of Laois and Roscommon.

FIGURE 2:
Age of carers



FINDINGS

FIGURE 3:
Counties
respondents
live in



FIGURE 4:
Type of area
respondents
live in

21%
Rural

19%
Village / Small town

60%
Large town / city

Caregiving Circumstances

Of family carers, just over half are caring for a parent (56%) while one third are caring for a spouse. ‘Other’ responses were those caring for in-laws. A relative majority of respondents (55%) live with the person with dementia. ‘Other’ responses (4%) included those who stay with the person they care for on an ad hoc basis and some have moved in with the person because of the pandemic. Some respondents reported that the person had moved into residential care in the past year.

Almost half of carers assessed the person with dementia as being in the moderate to middle stages of dementia with another large percentage (39%) rating the person as in the advanced to later stages of the disease. ‘Other’ describes those with rapid onset dementia, those who were unsure as they have “no help” or those who have passed away.

FIGURE 5:
Stage of dementia
(estimated)

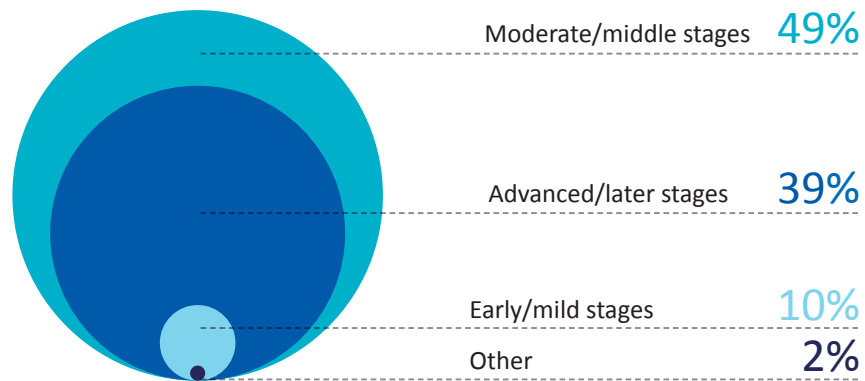
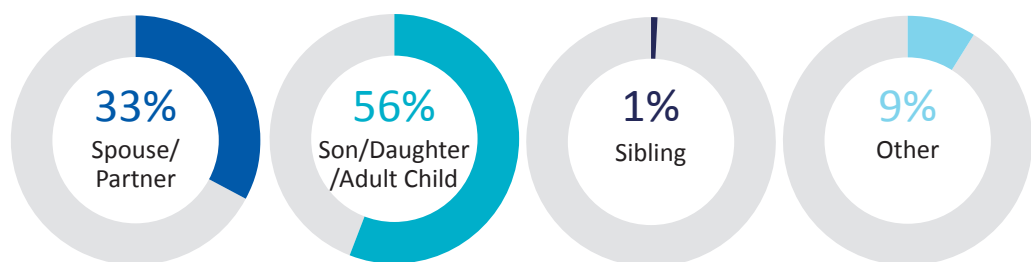


FIGURE 6:
Relationship to the
person with dementia



FINDINGS

Services and Supports

30% of respondents use ASI services though it should be noted this may be inflated due to this survey being distributed through ASI channels. 18% rely on support from neighbours and friends while 10% have support from community groups such as ALONE, Meals on Wheels etc. Several respondents (44%) selected 'other'. These other services and supports in order of frequency include:

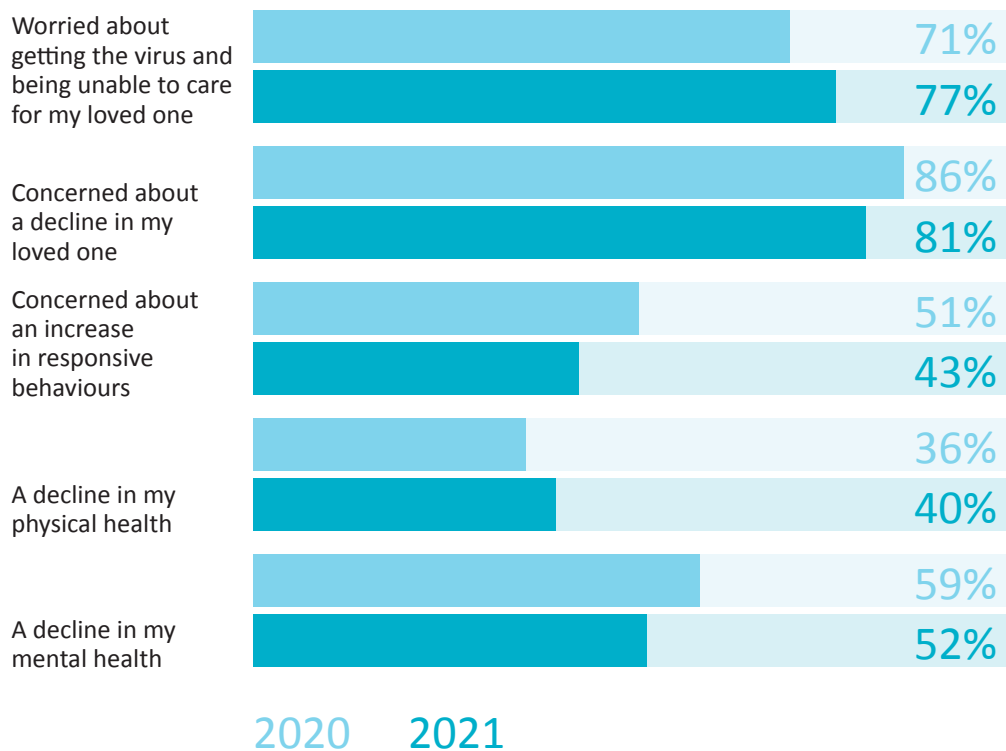
- The HSE e.g. Home Help, Homecare Package, Public Health Nurse (n=60)
- Family (n=30)
- No services/supports (n=23)
- Private Carers (n = 12)
- Five Steps Programme (dementia project in South Tipperary) (n = 4).

Concerns During COVID-19

Respondents were presented with a list of concerns and asked to indicate which ones, if any, they have been impacted by in the last year. Responses are very similar to July 2020 as demonstrated in Figure 7.

- **77%** of respondents fear getting sick and being unable to care for person with dementia
- **81%** of respondents feel concerned about a decline in the person with dementia
- **54%** of respondents have felt worried about how they will continue to cope

FIGURE 7:
Concerns of family carers in 2020 and 2021



Others areas of concern, not addressed in last year's report include,

- **41%** of respondents have felt worried about meeting the needs of other family members (aside from the person with dementia).
- **32%** have felt concerned about the postponement/cancellation of healthcare appointments for their person with dementia.

PEOPLE LACK CHANGE
FEAR INTERACTION SOCIAL
NEED CARE ISOLATION
BREAK COVID
TIME SLEEP
ROUTINE WORK RISK
PRESSURE SUPPORT
SAFE ANXIETY
FREEDOM DECLINE FAMILY
VIRUS LONELY

Key Challenges

We asked family carers and people with dementia to list their greatest challenges in relation to COVID-19.

Family carers highlighted the following,

- 1 Needing a break/respite
- 2 Loneliness and social isolation
- 3 Anxiety and stress related to caring workload and attending to competing priorities

This is largely reflective of the findings of the previous COVID-19 report in both March and July 2020 in which loneliness, anxiety, lack of support and routine were identified by both respondents with dementia and family carers.

For respondents with dementia the greatest challenges are,

- 1 A lack of routine
- 2 Struggling with activities of daily living such as taking medication, shopping, cooking etc.
- 3 Fear of contracting COVID-19
- 4 Feeling down and sad
- 5 Loneliness: missing friends, family and the activities they attended before COVID-19.

FIGURE 8:
Greatest challenges
affecting family carers
in COVID-19

FINDINGS

Exploring the Ongoing Impact of COVID-19

Respondents reflected on the above challenges and concerns, and described in detail what these mean for their everyday lives.

Increased Care Demands

As caring workloads have increased in the absence of services and supports, respite has been very limited. Social distancing and travel restrictions mean that family and friends cannot offer usual support while carers are working harder than ever to provide support and stimulation in the absence of formal supports,

“COVID-19 has taken the outlets away that help you cope. The caring role has become full time 24/7. It was particularly intense at the start as we isolated ourselves to ensure it didn't come into the house. A reduction in services meant there was no break and normal activities that give you space from the house, even work, were removed. It had a massive impact on our marriage too.”

Competing Responsibilities

Carers spoke of their difficulty juggling family, work and their caring responsibilities, particularly those with young children. They describe the impact of COVID-19 as “*utterly draining*”, feeling “*overwhelmed*”, at “*breaking point*” and recognise the significant toll on their families and relationships,

“I feel very tired by the time I get home and sometimes I find it hard to talk to the family and can be snappy, which is not fair. I think the tiredness is emotional.”

“I'm mentally broken with no carers support (because mum isn't yet vaccinated age 70) I don't have energy for my young kids and just about keeping my head above water with my employment.”

“I stay with my parents every weekend as no carers are available. I have 3 teens, so they sacrifice a lot while I am there. I feel pulled in lots of different directions.”

We asked respondents if their caring workload has impacted on relationships within their household, or how they are getting on with other people at home. 70% of those caring for a parent ‘agree’ or ‘strongly agree’ that their workload is affecting relationships at home, compared to 29% caring for a spouse or partner. Evidently, the impact appears far greater on those who are caring for a parent compared to respondents caring for a spouse. This is not unexpected considering that those

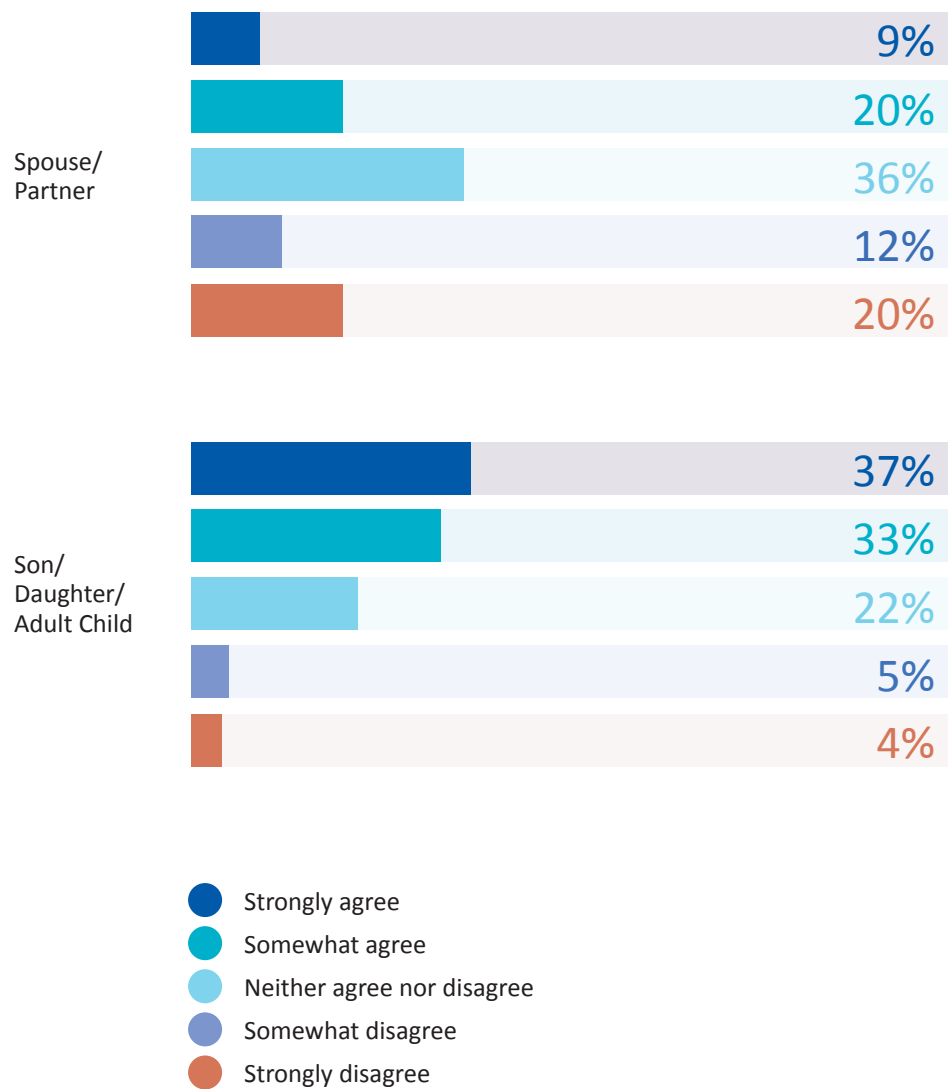
FIGURE 9:
Impact of
COVID-19
on family carers

ISOLATED
HUSBAND DAD
SUPPORT SAFE
WORK HOME
HARD FAMILY DAY
YEAR PEOPLE
BRING TIME LIFE BREAK
MOTHER WORRY
CONSTANT SOCIAL FRIENDS
RESTRICTIONS
DIFFICULT

FINDINGS

caring for a parent typically have other competing priorities and younger families of their own while those caring for a spouse tend to be older and perhaps retired.

FIGURE 10.
Impact of increased caring workload on relationships at home



Exhaustion and Burn-Out

Respondents report that they are exhausted from increased caring demands and feel an overwhelming sense of pressure and worry. There is constant guilt that they are not attending to all of the needs of the person,

“ I am past burnout, I had to take 3 weeks unpaid leave. I was so exhausted.”

In the focus group with ASI Staff, participants emphasise a growing crisis among family carers whom they notice are reluctant to reach out for help and support during COVID-19. They describe carers as becoming more introverted and disconnected. While online support was initially of some help, they observe that this is simply not adequate to meet carer needs and many family carers are so stressed that they now feel somewhat irritated by this offering, rather than supported. Although ASI services such as Day Care at Home are experienced as supportive and useful, as are block hours of home care, this level of support is inadequate and family carers require more support to cope with their immense caring workload. Many families remain on waiting lists for home care even during COVID-19, when there are only very limited other supports available. The deficit of appropriate services is a source of tension and strain for many families.

Stress and Worry

Many family carers report experiencing persistent stress and worry,

“ I feel complete isolation and worry constantly about keeping my mother safe. Feel exhausted, she is always on my mind. I worry constantly.”

Carers are very fearful that they themselves will contract the virus and be unable to care for the person with dementia,

“ Constant anxiety as to what happens to my loved one if I fall ill or if he got ill or deteriorated and needed hospital care and found himself alone in a strange space with no visitors so we cocooned to protect him.”

In order to minimise risk of the person with dementia contracting COVID-19, some family carers will not accept any outside help,

“ I am my husband’s constant companion. He is getting more dependent. I feel as we have no family I can’t turn to many people for help because of the restrictions. I am terrified of getting Covid. Who will look after him? He would go to pieces.”

FINDINGS

For carers with young families and work responsibilities, this challenge is especially acute,

“ Every choice I make now revolves around the risk it may or may not impose on my loved one. I am a teacher and my young son visits him with me. Both of us spend our days in environments where social distancing is not fully happening and this causes me worry.”

Guilt and Frustration

Family carers remark that they experience considerable guilt and worry that they are not doing enough for the person with dementia,

“ The effort balancing a workload and keeping Mam engaged cognitively. Frustration at the disease progression and the guilt of not managing to research/stay on top of additional help that might help Mam with her life skills.”

“ I am constantly worried about both my parents and feel whenever I am not with them, I am letting them down.”

Grief and Loss

Family carers describe a feeling a sense of grief, loss and helplessness as they watch the person with dementia decline,

“ He has lost all social skills and I cannot see him adjusting to social settings ever again. I feel, as a couple, we have paid a huge price, Covid robbed us of precious time.”

“ I have less time for myself and spend a lot of time worried about mam and can get quite down about it as Mam has regressed significantly as a result of Covid. She is disappearing in front of me quicker so there is a lot of sadness to deal with also.”

Rising Tension

DAs acknowledge that in some cases as family carers struggle to cope, tension arises and family members resent their caring responsibilities. A small number of respondents mention that they are less patient and tolerant due to burnout,

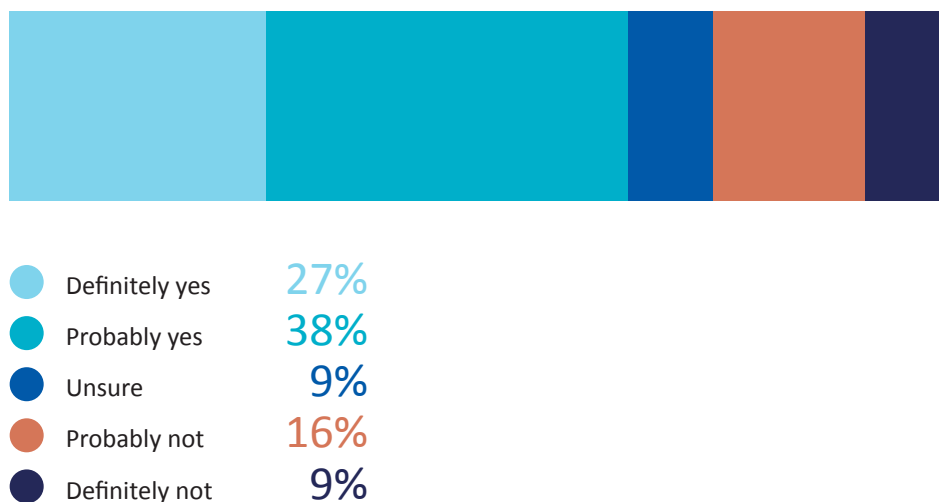
“ Losing patience with my Mam, trying to work and give her 100% of my time. Also a huge amount of guilt that I’m not doing enough for her. Also snapping at her a lot more than I was before the pandemic and then feeling so guilty for it. Watching her deteriorate over the year also and nobody else noticing it except me because I’m the only one who lives with her.”

Long Term Care

28% of family carers are considering or have considered a move to long term care over the past year. Of those 55 respondents, 65% say this move is sooner than expected due to COVID-19.

FIGURE 11:

Carer perspectives on whether a move to long term care for the person with dementia has come sooner than expected due to COVID-19



FINDINGS

Dementia Adviser and Staff Perspective

The focus group with DAs and other front-line service staff offers insight and context into the lived experiences of family carers and people living with dementia.

Changing Home Environment

The DAs and Service Staff remark that COVID-19 has brought about significant family changes, whereby in some cases all family members are at home together for long periods of time and adult children might have also moved home. This can present additional challenges and contribute to tension, especially if the primary carer feels unsupported by other family members. Extended family who may have been sharing some caring responsibilities previously can no longer visit. COVID-19 has, in many instances, compounded existing challenges and dynamics that were already under strain.

“ The age of carers now are much younger than what they were so many years ago, you know? They can't give up their jobs, they have the full mortgage, they have young kids and they have school going kids, whatever, they have college fees. So if all of that on top of caring, being a full time care for their mom or dad yeah very different one was years ago.”

Deepening Crisis

Terms such as “struggling”, “suffering”, “crisis” are used to describe the carer experience. Front-line staff believe that exhaustion and burn-out among carers are leading to apathy and detachment, and this might mean that some family carers will be reluctant to re-engage with services once they re-open. They explain apathy and a lack of motivation among some family carers,

“ It's very hard for the person who's caring for someone with dementia to summon up all the energy and enthusiasm to do some of those activities that we suggest. It can be quite hard. If you're there all the time, you don't have the energy to initiate the activities.”

“ There is concern there for the person with dementia and concern for [the carer] and it just and the two of them just live on their own and they're isolated and he's really struggling you know just the two of them and the repetition of it.”

“ She just feels it's broken her. That's how she describes herself to me you know she feels it's broken her.”

Postponed Medical Care

DAs highlight missed medical and healthcare appointments among people with dementia and also their family carers are a key concern. This is especially problematic for people affected by dementia, as the progressive nature of the disease can have an enormous impact on families, and can lead to crises, if not addressed in a timely way. They describe medical appointments being postponed by several months and in many cases families are already struggling to cope and deeply concerned about the health and wellbeing of the person with dementia, even at the point when the appointment is cancelled.

The DAs explain that some medical issues among people with dementia are being missed or overlooked and simply being “*dismissed as dementia*”. They are observing a quicker decline in symptoms of dementia, and also point out that some nursing home admissions are happening sooner compared to pre-COVID-19 times as families struggle to cope.

Growing Need

ASI Staff identify those who were diagnosed with dementia during or prior to COVID-19 as a vulnerable cohort in particular need of support. Many have had limited follow-up appointments or supports, and are experiencing “*enormous stress and anxiety*”. Some are people with young onset dementia and young families, and are living in immense fear for the future. The DAs also identify a cohort who are struggling to access services for diagnosis during COVID-19, and usual supports and services. Many of them need psychological support and the DAs observe that “*life has become frightening for these families*”,

““ There’s a whole generation of people who are being diagnosed now and there is nothing. There’s nothing there and I can’t remember a time where we’ve been in a situation like this. We’ve always had some services to offer but there is nothing and when we come out of this whenever that will be the impact for those people will be enormous.”

FINDINGS

Carer Wellbeing

The DAs express concern about the mental health and wellbeing of carers, noting an increase in mental health issues, including depression and suicidal thoughts. They explain that in the absence of services, many family carers spend much of their days sitting with the person with dementia, unable to leave their homes for respite. Low self-esteem, apathy, depression and boredom are common among family carers. One DA gives an example of a female carer, a young mother in her twenties caring for a parent with dementia. Without adequate support, she experienced exhaustion and severe stress and was admitted to a psychiatric facility. She was discharged into the same environment without any additional services and carer supports.

Loneliness, Isolation and Deteriorating Health

Family carers report feeling lonely and isolated with nowhere to turn for support,

“ The isolation is horrendous... no one to talk to... Not being able to go out just to get away from it all for a little bit. My blood pressure is sky high and I fear for my own health now. Having to consider nursing home care just because of feeling burnt out.”

“ Lonely and upsetting with no hope of help or assistance or even time off. Own health declining but no time to look after self or get sick, worry of having to isolate, who will take over.”

Feelings of sadness and loneliness are recurring themes in the respondents' accounts,

“ Days are so long with no one to talk to as my husband cannot hold a conversation.”

Approximately 20% of carer respondents are over the age of 70, and many already experience health problems. Respondents indicate that their physical and mental health is deteriorating,

“ My health has got worse – trying to keep hospital appointments has been hard. I have felt very low and very alone at times.”

Despair and Depression

Respondents' sense of *"despair"* and being *"with no hope"* is stark and poignant,

“ I have become more introverted and have lost my sense of hope ...doesn't seem to be light at the end of the tunnel.”

“ I am basically on my own. I have asked our children not to come into the house because I am afraid of us getting Covid. They try to drive by but with the weather being cold we don't see them for any length of time. So it's lonely sometimes.”

“ I feel broken, with anxiety and depression.”

Some respondents are very concerned that they cannot support the primary carer of the person with dementia (generally an older parent) and comment that caring and COVID-19 is having a negative impact on both of their parents,

“ I worry about the burden on her main carer, my father in his 80s, and his ability to continue to provide care, particularly as opportunities to get a break from the house and meet his peers are virtually non-existent due to the public health restrictions and residential respite is no longer available.”

One respondent aptly summed up the the carer experience 12 months on,

“ My workload has increased dramatically...as I have to work harder to keep my parent stimulated and well.. This has meant exhaustion at times.. Impatience at times, hopelessness at times.. This also means my own family is suffering as they have to pick up the pieces when I cannot cope.. It has made me realise that carers are not valued for the work they do... We are not a priority.”

FINDINGS

The Impact of COVID-19 on People Living with Dementia (Perspectives of DAs, ASI Staff and Family Carers)

Acceleration of Symptoms

The DAs confirm that for many people with dementia their symptoms have accelerated, and describe as “*shocking*” the pace at which this is happening,

“ It might sound obvious too but without activities, without that stimulation their condition is progressing and they’re going to go downhill at a faster pace at a quicker pace than they would have otherwise.”

Almost all family carers echoed the concern that they have observed symptoms decline significantly and rapidly since the beginning of the COVID-19 Pandemic. Prior to COVID-19 many people with dementia had lived vibrant lives despite their diagnosis. Family carer accounts paint a devastating picture of the impact of COVID-19,

“ But this time last year she was able to go into the city and pay her bills and get her shopping. She has lost her independence since Covid. She now depends on me. She can’t prepare her own meals. And can’t remember if she has eaten.”

“ I think the year of isolation has sped up the illness, the lack of socialisation through meeting family, friends and her weekly day centre visits hasn’t been good cognitively or physically. Her sleep and physical agility has definitely deteriorated and I worry about the quality of life she is living as her Alzheimers takes over. This has certainly quickened our need for full time care which we are in the process of applying for.”

COVID-19 guidelines and requirements such as wearing a mask and social distancing present challenges,

“ The deterioration in the person I care for continues, his social skills are now non-existent due to Covid restrictions. He did not understand social distancing, mask wearing etc so I had to stop him going out. He was independently shopping etc March 2020 and now cannot leave home on his own.”

Loneliness and Lack of Interaction

Family carers acknowledge that loneliness, loss of social activities and friends are deeply felt by the person with dementia. Similarly, the vast majority of staff who deliver Day Care at Home to people with dementia observe that loneliness and isolation are notable challenges for this cohort,

“ He is a very sociable person, who loves to chat, meet people, tell jokes, stories etc. He has found cocooning very, very hard.”

“ He is lonely as his friends can't call, at first I think he thought we were making up Covid to keep him in his routine included coffee shop outings in the morning.”

Anxiety and Confusion

Many people with dementia do not understand the restrictions of COVID-19 and feel abandoned and isolated. Many worry that they have done something to upset their friends and family who can no longer visit,

“ I can actually see how more confused and anxious my father has become because of the lack of outside contact, he feels he has done something wrong that his friends and neighbours are not calling into the house any longer.”

A lack of cognitive understanding and awareness of COVID-19 restrictions and resulting boredom can lead to frustration, agitation and tension, putting pressure on family relationships,

“ Constant tension because she forgets about Covid and thinks I am making the rules about masks, distancing etc.”

FINDINGS

Social Withdrawal and Apathy

Another facet of the restrictions is evident as family carers describe how the world has become more introverted and narrow for the person with dementia and they are now more anxious and fearful. Others no longer yearn to see friends or go out, rather they are feeling a sense of apathy and unmotivated after a year of restrictions and isolation,

- “ Mum has become a lot more withdrawn in herself as she has no physical interaction with her grandchildren or friends either in her own home or elsewhere. Lack of stimulation and cognitive engagement has had a dramatic effect on her.”
- “ Deterioration due to lack of social interactions from visitors and availability of health services.”
- “ Higher levels of anxiety and difficulty getting them outside.”
- “ Having little or no social interaction has affected personal care, for example showers has reduced slightly in priority, it's like he can't be bothered because he won't be going anywhere or seeing anyone apart from about 3 people....I believe that if Covid had not come to us, that my father would not be deteriorating so quickly.”

Cancellation of Appointments

Cancellation of medical and health appointments is a persistent cause of concern for family carers, also identified by DAs. The DAs acknowledge that cancellations are happening when people desperately need support and services and are already at crisis point. Often appointments are postponed for a number of months, a source of anxiety and frustration for many families. Many family carers comment that the physical health of the person with dementia has declined significantly as a result of postponed appointments and reduced medical supervision. Their mobility has also decreased significantly as restrictions mean they are unlikely to leave the house to go shopping or accompany family on errands or activities,

- “ Ended up in hospital due to cancelled hospital appointments. He nearly died due to usual lack of observation by [the] medical team.”

Challenging Hospital and Nursing Home Environment

The DAs point to a move from a person-centred approach during COVID-19 to a medical model. They observe a much stronger emphasis in nursing homes on disease control and bureaucracy, which can undermine person-centred care. One DA explains how a family carer experiences this in a long-term care setting,

“ She (family carer) actually says which said it (nursing home) was like prison. She said they couldn't come out of the room. It was the same breakfast every day and staff weren't taking the time to talk to her (mother with dementia), the staff are run off their feet and they're filling in forms for this and for that. The same applied to people who are in hospital, no visitors... Someone could be in for a few weeks and haven't seen them (pwd). They are now being told maybe (they can visit) but then their condition has deteriorated.”

The hospital environment during COVID-19 brings profound challenges for people with dementia, most of whom are unaccompanied by family members. Confusion, anxiety and distress are all highlighted by the DAs on the part of the person with dementia, while family carers are stressed and anxious, having limited communication and understanding of how their family member is coping without visitation and support from a familiar person,

“ Communication with the person with dementia and not knowing once the ambulance leaves, where they are how they are and not being able to see them not knowing if you'll ever see them again. The stress of that is enormous, once that door closes and they're been taken away from everything they know and are being brought into a strange environment. We know that in a hospital environment, for people with dementia it's less stimulating and it's confusing for the person. We know that people can decline in hospital.”

FINDINGS

A positive Impact

A small number of family carers commented on how COVID-19 has not had any impact on the person with dementia. In fact, two respondents feel it has a positive impact as the person with dementia is surrounded by less noise and not confronted with situations they do not understand or recognise. This seemed to be particularly true for those with more advanced dementia,

“Dad is actually doing better mentally since the outbreak of the pandemic. Physically he has got a little bit more frail. He was used to spending a lot of time at home anyway and now has more company than before, since I am spending 3 to 4 days a week with him and involving him in more activities.”

Positive Supports

Several family carers emphasise their appreciation for the support they have received from The ASI. One respondent, 32-year old single mother who is caring for her own mother with dementia explains,

“Thank you for existing! ...It's great this organisation. It is the worst disease I have ever witnessed and I don't think you properly understand it unless you live with it.”

Some refer to the important of support from DAs and Day Care at Home service,

“The Dementia Advisors were a great help on my journey so far with good advice and practical guidance...I will always be indebted to them for their kindness and an ear to listen when i needed help for my Mam.”

FIGURE 12:
Impact of COVID-19 on
person with dementia
(according to family
carers)



FINDINGS

Perspectives of People Living with Dementia

When we asked people with dementia what they feel the impact of COVID-19 has been, similar themes are identified.

Lack of Routine

For most respondents, their usual activities or services are currently suspended meaning their routine is affected. Although COVID-19 has been with us for a year, their activities were anchors for routine and it has been difficult to create new ones. They also note the importance of mental stimulation,

“Lack of interaction, lack of normality, would have been going to Centre and other meetups, The Choir, all those structures are gone.”

“I’m not very good with my medication. Routine guides me. With Covid-19, routine is completely gone so my taking of medication is disrupted. Routine is very important for people with Alzheimer’s.”

“There is a lack of stimulation with the services closed. I miss the activities.”

Loneliness and Isolation

Many respondents with dementia are feeling lonely, abandoned and isolated due to the COVID-19 restrictions. They feel trapped and confined at home, particularly those living alone. Those who are living with family highlight how grateful they are to have somebody at home to support them,

“I can’t meet my friends, I can’t go to the beach, I’m tied to the house. Loneliness and isolation, it’s cruel.”

“I have gotten very down, feeling nobody cares about me.”

“I get very down in the dumps at times, when you are not going out and mixing it is very hard.”

“I would be dead without my dog, he is great company.”

Struggling with Daily Living

Some respondents spoke of how they struggle with taking medication, cooking and using appliances. Again, this particularly affects those who are living alone. Due to COVID-19, they do not have usual visitors or supports that they relied on in the past,

- “ [I] feel lucky to have a family member at [my] side as [I] don't know how I would have coped without them staying as no other source of help.”
- “ The worst part for me is being alone and not having help to sort out little things like the tv. Then I can't watch the news or see what is happening and I get frustrated and upset. I would like to put on music to cheer myself up but I can't work the CD and there is no one to help me.”
- “ Covid does not bother me but i am worried about living on my own because I can't manage my tablets.”

Fear of COVID-19 and Restrictions

People with dementia are worried and afraid of contracting COVID-19. Complying with restrictions is another significant source of worry,

- “ Anyone coming you would be afraid to catch COVID – you worry and you don't want to hurt people's feelings.”
- “ It has been stressful around the rules and trying to keep safe.”
- “ I have fear of being stopped by the police for violating restrictions.”

For one respondent with dementia, it has led to them choosing to spend more time at home,

- “ It is hard to remember to wear masks and I must wear them when I go out. For me the distancing is hard to remember – I prefer to watch my DVD's. I stay at home more now.”

FINDINGS

Coping During COVID-19

Family Carers

Although one third of family carers consider themselves to be coping well, 41% describe their coping as 'average', while approximately one quarter admit they are struggling. These results are very similar to our findings in July 2020. No respondent selected 'excellent'. Interestingly, when asked how they feel they are coping during the last 12 months, 44% of family carers report feeling less able to cope as the time passes, while 21 % feel better able to cope.

FIGURE 13:
Carers self-reported coping during COVID-19.

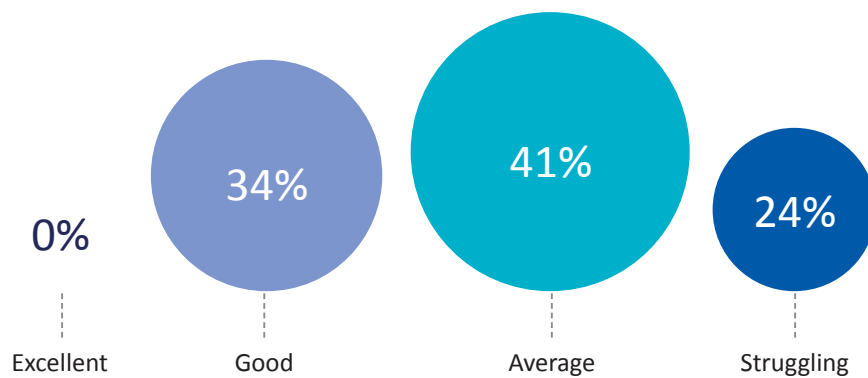
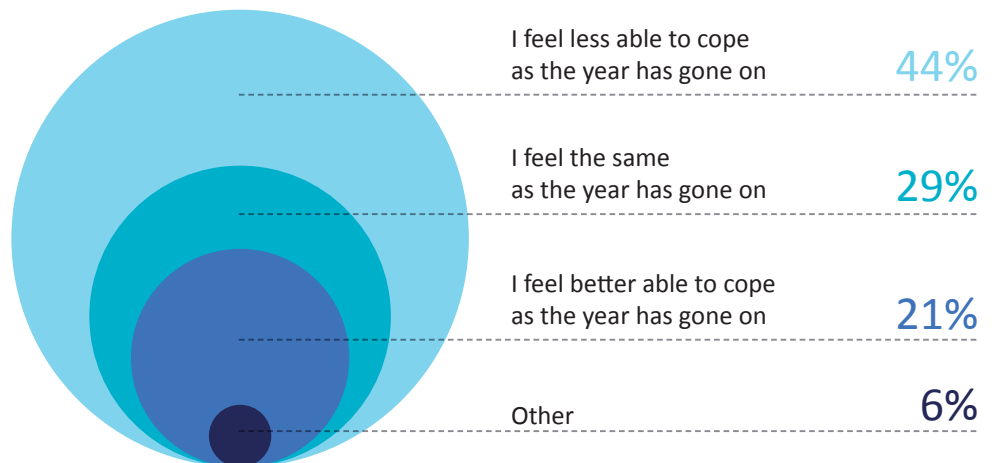


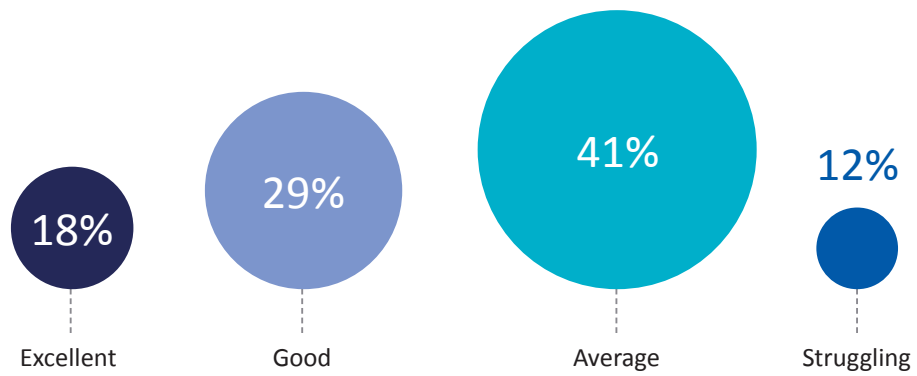
FIGURE 14:
Carer ability to cope (self-reported)



People with Dementia

Almost half of the respondents with dementia consider themselves to be coping well or even excellent during COVID-19, while 41% describe themselves as average while 12% are struggling.

FIGURE 15:
How people living with dementia felt they were coping during COVID-19



FINDINGS

Understanding Distress

We asked respondents what they feel the most upsetting thing about the COVID-19 Pandemic has been.

Worsening Circumstances

COVID-19 has had a profound impact on family carers of people with dementia,

“ Covid has made a hard situation extremely harder. We had to make a lot of difficult decisions.”

Of concern, respondents describe “*worsening*” circumstances, and an almost complete lack of options for support. Even current available options are not preferable because of COVID-19,

“ As things get worse with mom, even if that is just in the normal course of her condition, we feel we have no options. We can’t send her to residential care as we would not be able to see her. We can’t get respite care or day care centers. We can’t improve her quality of life through activity and socialisation. Everything is worse.”

Family carers describe feeling “*terrible anxiety*”, “*devastated*” and being “*heartbroken*”. They see themselves as rendered invisible,

“ I feel no one cares about us here.”

Abandoned by Government

Respondents report feeling “*forgotten*” and “*abandoned*” by the Government and are frustrated that people with dementia and family carers are not being prioritised for the COVID-19 vaccine,

“ Shocking that the government has not prioritised people with dementia for access to the vaccine.”

A male carer explained his frustration,

“ I am over 80 and [my wife] has Alzheimers. I think that is a disgrace. We are waiting, waiting. We should have an approximate date at least.”

96% of family carers believe that those caring for people with dementia should be prioritised for the vaccine. Respondents view this lack of prioritisation as indicative of the lack of value placed on the role of carers,

“ Carers being abandoned by our government, not even considered a place on the list for vaccination... Carers have no voice, but give up their lives to allow someone to remain at home. The state saves a fortune so carers should be looked after too.”

“ We carers of Ireland save the Government millions annually. They do not prioritise or consider us carers for the vaccine. Outrageous.”

Betrayal and abandonment are also expressed relating to lack of supports and services,

“ I will never forget how we were abandoned when we needed support most, carers were invisible before Covid, its got 100 times worse for carers during Covid.”

Some family carers perceive the Government has having “*a total lack of empathy*” for their plights. Others call for recognition of the vital role of carers,

“ Carers need to be recognised for the care they provide. Including financially. Not be penalised for giving up work to care for parent/sibling etc.”

Similarly, 92% of respondents with dementia say they do not feel supported by the Irish Government during COVID-19. The perception of abandonment and betrayal by Government and anger over what participants view as a lack of support and recognition is palpable in the research findings and is more acutely expressed than in the previous COVID-19 reports in 2020.

FINDINGS

Inadequate Services

Family carers are deeply angry about the perceived lack of support and services,

“ It is a disgrace how carers are treated in this country, we were already struggling... you have to fight for everything at each point, hospital bed, hoist etc, this got worse during Covid, I feel Covid can now be used as an excuse for a system that does not support people to live and die at home.”

Respondents cite a consistent lack of services throughout COVID-19 as frustrating and deeply concerning,

“ A year is too long to not have blood pressure etc checked and can only lead to problems/ill health further down the road.”

Several family carers emphasise the need for Day care and other dementia supports and services to resume,

“ Life is not easy for anyone but caring for someone with dementia is extremely difficult and the HSE and the Government need to do more to provide support and assistance to Carers and support the Alzheimer’s society of Ireland and other Support Groups.”

Decline in the Person with Dementia

The majority of respondents feel the most upsetting thing about the COVID-19 Pandemic is the irreversible negative impact it is having on the person with dementia. There is a strong sense of helplessness and loss as respondents report watching person decline before their eyes,

“ Witnessing my dad’s decline especially in his mobility and knowing he won’t know the grandchildren and great grandchildren when they get to see him again.”

Respondents’ description is almost palpable and deeply poignant,

“ See my husband deteriorate in front of my eyes.”

“ Not being able to be with my parents all the time – just want to hug them – I think touch is so important for mental health and we’re really missing out on that.”

Visiting Restrictions

Some respondents describe feeling distraught that their family member has moved to long-term care because they struggled to cope with the caring workload. They are now restricted from visiting the person with dementia. Visiting restrictions are a source of immense upset,

- ““ It was as if the government decided that I was more of a risk to my Mum than Joe Bloggs, healthcare assistant. This is something I will never ever forget.”
- ““ Not being able to see my husband now that he is in long-term care. He is non-verbal and I am outside the window trying to communicate – this is very hard.”

Fear of Contracting COVID-19

Similar to findings in last year's Caring and Coping with Dementia During COVID-19 Report, a large number of respondents are fearful that the person may contract COVID-19 and that a stay in hospital will cause an even more rapid decline in their dementia. Many respondents are fearful of being unable to visit if the person is admitted to hospital while others family carers worry about what might happen if they get sick themselves. Many agonise over whether they should visit the person with dementia as they are fearful of passing the virus on, all the while aware of the person,

- ““ Deterioration in my mother's health and care during the first few months of Covid-19 when my siblings and I stopped calling to the house for fear of transmitting virus.”
- ““ The creeping sense of dread that something might happen to me and leave him vulnerable.”

Isolation, loneliness and a lack of support are cited frequently by respondents, as above, as one of the most upsetting aspects of life during COVID-19.

WORK HOME
FAMILY DA
PEOP
ME LIFE BREA
OTHER WORRY
CONSTANT
SOCIAL FRIEND
RESTRICTIONS

Supports Needed

People with dementia

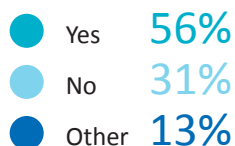
88% of respondents with dementia feel they have enough practical support while only 56% feel they have enough emotional support. Almost one third of respondents with dementia (31%) do not have enough emotional support. 'Other' responses include the need for more local support in rural areas and financial support. This bears similarity to last year's Caring and Coping with Dementia in COVID-19 report, in which half of people with dementia said they need emotional support while 21% said they need practical support.

When asked to elaborate on what kind of supports they need, responses included

- Somebody to talk to
- Services to reopen
- Home care or home help

Respondents with dementia feel very supported by family and friends (93%) and by Health and Social care Professionals (77%). An overwhelming 92% do not feel supported by the Irish Government while there is an even split on feelings of support from local charities.

FIGURE 16:
Responses to
'Do you have
enough emotional
support?'
(respondents living
with dementia)



FINDINGS

FIGURE 17:
Responses to
'Do you have
enough practical
support?'
(respondents living
with dementia)

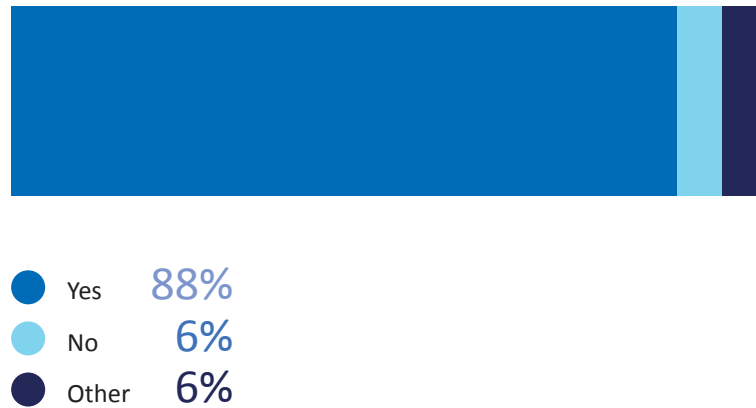
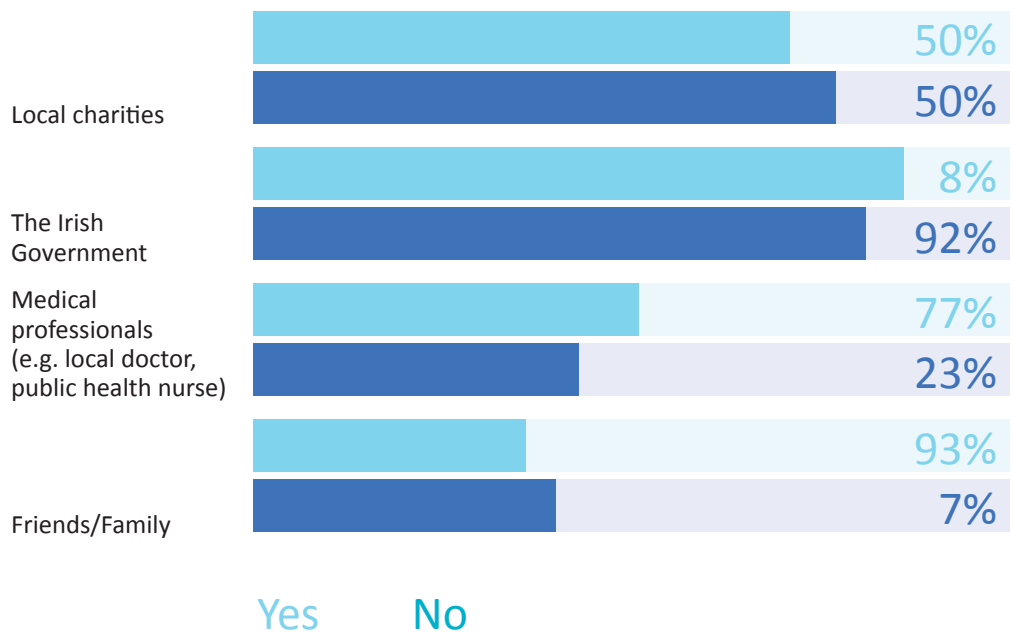


FIGURE 18:
How much
respondents living
with Dementia
felt they were
supported by
different groups

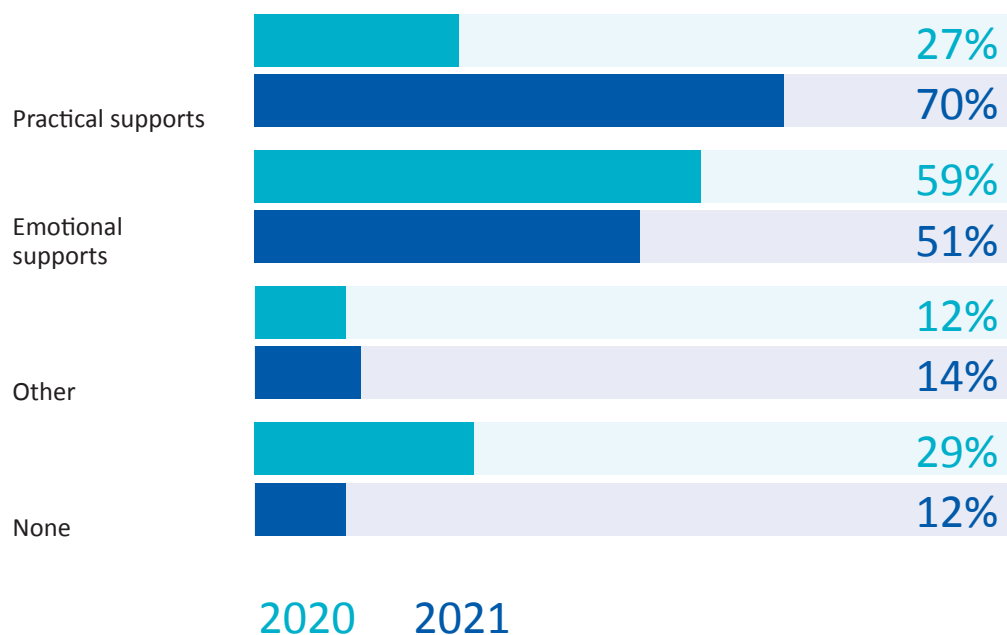


Family Carers

We asked respondents to select what kind of support, if any, they need as a carer in COVID-19.

The need for practical supports almost tripled from July 2020, seeing a rise from 27% to 70% today. A similar percentage of respondents selected emotional supports in 2021 (51%) compared to this time last year (59%).

FIGURE 19:
Support needed
by family carers
in 2020 and 2021



14% of respondents selected 'other' and these responses included,

- Home care or home help from the HSE to allow the family carer to have a break
- Home visits aimed at stimulation and activities for the person with dementia
- Financial support
- Support in making decisions around future care for the person with dementia

ON CHANGING
RESOCIAL
DILATION
// CO

KEY FINDINGS

- COVID-19 and associated restrictions have led to a significant and largely irreversible deterioration in people living with dementia. For many, their world has become a smaller and more frightening place.
- Family carers continue to be at breaking point and some have surpassed it ending up in hospital or psychiatric care. Their mental and physical health is suffering while their other relationships and priorities pay the price.
- 40% of family carers report a decline in their physical health, while 54% report a decline in their mental health due to the impact of COVID-19. Dementia Advisers report that they are encountering more people who are experiencing suicidal thoughts.
- 54% of family carers have felt worried about how they will continue to cope, while 44% report feeling less able to cope as the time passes.
- 81% of respondents feel concerned about a decline in the person with dementia.
- People living with dementia urgently require face-to-face services such as day care centres and social clubs while their families are in desperate need of respite.
- People with dementia and their families continue to experience pervasive loneliness and social isolation. Both people with dementia and family carers cite loneliness as one of their greatest challenges of COVID-19.
- Families are hugely fearful of what might happen to the person with dementia should either person fall ill with COVID-19. This is compounded by visitation restrictions in hospitals and healthcare facilities. 77% of carers fear getting sick and being unable to care for the person with dementia.
- Carers' need for practical support has almost tripled compared to July 2020 rising to 70%. Over half of carer respondents report needing emotional support.
- People with dementia and their families feel abandoned and betrayed by the Irish Government. The lack of vaccine prioritisation for informal carers has been a final affront for many.
- 28% of family carer respondents have considered a move to long term care for the person with dementia over the past year. 65% of these say this move is sooner than expected due to COVID-19.

KEY RECOMMENDATIONS

Arising from these key research findings, the following practical and policy recommendations should be acted upon in order to address the needs of people living with dementia and family carers. It is notable and telling that these recommendations bear much similarity to those set out in the July 2020 report, *Caring and Coping With Dementia During COVID-19*.

- 1** The absence of usual services such as day care services, support groups, Alzheimer cafés and cognitive stimulation therapy has impacted significantly on people living with dementia. The reopening of face-to-face services and supports in particular day care and support for family carers, needs to be explored as a matter of urgency. The ASI's 2020 evaluation of its day care services (to be published) emphasises the wide range of benefits of day care and makes key recommendations that can inform guidance for resumption of this service.
- 2** 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. People with dementia have unique and complex needs. The nature of dementia and the ways in which symptoms can develop rapidly leaving family carers distressed indicate that it demands a response that is timely and appropriate. Throughout the pandemic a timely and person-centred approach has been lacking. Public policy discussions relating to COVID-19 should include people living with dementia who have been adversely affected by the cessation of services and supports. The complex needs of those living with dementia in both the community and in residential settings should be addressed.
- 3** Given the severe level of unmet need among family carers, public policy should centre on supporting family carers who have continued to shoulder a disproportionate care workload over the last twelve months of the COVID-19 pandemic and are themselves now experiencing ill-health. Appropriate services and supports need to be implemented immediately to address the caring crisis arising from COVID-19. This should include respite services, crisis prevention care and therapeutic services including counselling.

- 4** Planning and investment is essential to meet an increase in service demand. Demand and need from those previously using dementia services will increase significantly due to the deterioration in health of both people with dementia and their families. Those who have been diagnosed with dementia during the pandemic are also in need of urgent support. Similarly, the needs of many people with dementia are now greater after a year in lockdown. More person-centred services aimed at those in later stages of dementia are required such as Day Care in the home.
- 5** Before COVID-19 there was a serious shortage of home care for people with dementia and this issue is still ongoing. The ASI's Day Care at Home service, which has been recently evaluated (to be published) indicates the benefits and positive outcomes of this service for people with dementia. This service with emphasis on the specific needs of the person, rather than simply on task-driven care, needs to be adequately funded and resources in the long-term. Moreover, the statutory home care scheme should be piloted and developed without further delay.
- 6** Prior to COVID-19, the 2018 Mapping report mapping dementia-specific services across Ireland indicated that no county in Ireland has a minimum standard of services, as mentioned. Investment in and planning of dementia services is now all the more urgent and must be prioritised immediately. The National Dementia Strategy should be fully implemented, and there needs to be a strong commitment from Government to investment in its implementation.

CONCLUDING RECOMMENDATIONS

This research set out to uncover the experiences and needs of people affected by dementia, one year on from the closure of service arising from the COVID-19 pandemic. Once again it has brought to the fore the plight of carers and people living with dementia, highlighting the consistent and ongoing daily challenges of this cohort including exhaustion, burnout, anxiety, grief, helplessness and despair. The only difference between these research findings and those of the July 2020 report, *Caring and Coping With Dementia During COVID-19*, is the heightened degree of these emotions coupled with deep-seated anger and resentment at the perceived lack of urgently needed support and services. For many family carers and those living with dementia, there have been no improvements in the intervening twelve months, and in fact, their circumstances and quality of life has only deteriorated and become even more precarious.

While COVID-19 has affected every facet of society, it has made an already vulnerable cohort even more helpless and exposed. Many of us feel loneliness, isolation and struggle with a lack of routine due to COVID-19 but for family carers there is no respite and no break. In addition to the everyday challenges that we are all experiencing, many family carers are struggling with a disproportionate workload. This has come at a significant cost to family carers' health and wellbeing, many of whom are enduring declining mental and physical health.

Social interaction, meaningful engagement and stimulation are critical to sustaining the wellbeing of people with dementia. These research findings suggest that the lack or absence of stimulation has brought about irreversible cognitive impairment and harm to people with dementia. This is also having a profound impact on the mental health of carers as they contend with grief and powerlessness as the person declines.

The sense of anger and frustration among family carers is evident by the sheer number who participated in this study and who were eager to include in-depth descriptions of their experiences and difficulties. That some stated that they were too frustrated and upset to detail their experiences is further insight into the devastating impact of the lack of support throughout the COVID-19 pandemic. Others simply pleaded for empathy and recognition, *"Please walk in my shoes... And value me."*

In both previous 2020 COVID-19 research reports, family carers expressed fear that they would be forgotten. This fear continues to be realised for many, and perhaps this is further evidence of the stigmatised nature of dementia. It is deeply disappointing that recommendations of the July 2020 report *Caring and Coping With Dementia During COVID-19*, have not yet been acted upon, and this report repeats most of these recommendations.

The ASI has maintained that no county in Ireland had minimum basic services for people with dementia and family carers. During COVID-19 limited services have been further diminished, leaving many families in crisis. The COVID-19 pandemic has not caused this crisis, rather it has illuminated the sparse and scarce nature of dementia service provision. Online and remote services are not sufficient to address the new and increased needs faced by those living with dementia. Face to face services must be re-designed and re-developed in order to respond to the pre-Covid and post-Covid challenges for those living with dementia and their family carers. They have been asking, waiting and struggling for too long. Their right to appropriate and adequate care and service provision is critical and must be addressed immediately.

Acknowledgements

We are really grateful to all of the people living with dementia and family carers who took the time to share their personal experiences and stories with us. We are also grateful to our ASI colleagues who participated in focus groups and supported the data collection process.

This research was carried out by The ASI Research Team, Dr Bernadette Rock and Dr Laura O'Philbin with the assistance of Ms Ciara O'Reilly, Ms Angela Miller and PPI Contributors Ms Helena Quaid, Mr Tony McIntyre, Mr Kevin Quaid, Mr Daithi C and Mr Sean Mackell.

PEOPLE LACK
FEAR INTERACTION

NEED CARE
ISOLATION

TIME BREAK

ROUTINE WORK

PRESSURE SURVIVAL

SAFE ANXIETY

FREEDOM DECLINE

VIRUS ISOLATION



THE ALZHEIMER
SOCIETY *of* IRELAND

The Alzheimer Society of Ireland is a national service delivery and advocacy organisation. It is person centred, rights based and grassroots led with the voice of the person living with dementia and their carer at its core.



Phone: 01 207 3800



Web: www.alzheimer.ie



Twitter: @alzheimersocirl



Facebook: TheAlzheimerSocietyofIreland



Instagram: @Alzheimersocirl

**The Alzheimer Society of Ireland Helpline
is open six days a week**

Monday to Friday 10AM – 5PM and Saturday 10AM – 4PM

Call 1800 341 341 or email helpline@alzheimer.ie

WITH
ISOLATION
DAD
STIM
DI
MOTHE
MIS
PROGRES
FAMIL
FRIENDS
LIFE
PEO