



## Caring & Coping with Dementia COVID-19: July 2020

### Plain Language Summary

#### Background

The COVID-19 Pandemic forced The Alzheimer Society of Ireland (ASI) and many other organisations to temporarily close most of their dementia-specific services including day care, social clubs, Alzheimer cafes, and support groups. Three months ago, The ASI published a report saying that people living with dementia and family carers are struggling with:

- Loneliness and social isolation
- Worsening symptoms of dementia due to a lack of routine and stimulation
- Fear and anxiety
- Carer stress and fear of being unable to cope

In June 2020, The ASI carried out more research to see if the situation has changed. This report presents the findings of that research.

#### Research Aims

1. Explore the experiences and needs of people with dementia and carers in the COVID-19 Pandemic
2. Understand how these needs can be addressed

## What we did:

1. Telephone and online surveys with 15 people living with dementia and 126 informal carers (i.e. family members/friends)
2. A focus group with five Dementia Advisers who work for The ASI
3. Looked at anonymous information from The ASI National Helpline

## What we found

COVID-19 is having a serious negative impact on people living with dementia and family carers mainly due to closure of dementia-specific services and activities.

Family carers are in crisis and people with dementia are experiencing a sharp decline in health as vital services stay closed.

## Impact of COVID-19 on Services

- Delayed or cancelled medical appointments affected over half of respondents.
- Almost half of respondents experienced the closure of day care services, 42% experienced the closure of support groups and activities for both the carer and person with dementia and 26% experienced closure of respite services.
- 22% of respondents experienced a reduction in home care and over one quarter chose to stop home care because they were worried about the home care worker bringing the virus into their homes.
- 19% of family carers 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.

*“Our home care was totally withdrawn at the start of Covid... 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.” (Family carer)*

## Impact of COVID-19 on Health & Wellbeing

Our research findings show that living in lockdown has taken an enormous toll on the health and wellbeing of people with dementia and their carers. This has become worse as COVID-19 dementia-specific services are still closed despite other lockdown restrictions lifting.

- 77% of family carers have had an increased caring workload since COVID-19. Their own families have not been able to help out and there are no services available. This is leading to burnout and stress.
- Family carers are extremely worried about catching the virus and not being able to care for the person with dementia. People with dementia who understand the virus are also very fearful.
- The majority (86%) of carers feel grief and loss as their loved ones' symptoms of dementia become worse due to a lack of stimulation from having no services available and cocooning. This has also led to an increase in responsive behaviours, fear, agitation, insomnia, and anxiety for the person with dementia.
- People with dementia and carers feel lonely and isolated. This is made worse by being unable to attend local activities and services in their community. People with dementia report feeling '*trapped*' and '*confined*'. Some do not understand COVID-19 and feel abandoned by their families and friends who cannot visit.
- Both people with dementia and carers are concerned about a decline in their mental and physical health. Carers also worry about their increased caring taking a toll on their marriage and family life.

*"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 has been detrimental to my mother. She has become more withdrawn, frail, increased confusion and anxiety. Mobility has declined too and incontinence has increased"* (Daughter caring for parent)

*"I cope well, but I drink (alcohol) to cope with my mother's dementia and all the workload."* (Son caring for parent)

*"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)

### **Greatest Challenges**

We asked respondents about their greatest challenges in COVID-19. These were:

1. Anxiety (including financial, family-related, work-related)
2. Social Isolation and Loneliness
3. Boredom and Lack of routine
4. Lack of support

## Dementia Adviser Perspectives: Supports & services

Dementia Advisers work with people with dementia and carers to provide a responsive and individualised information and signposting service. They provided insights from speaking with numerous families across Ireland.

- People are continuing to be diagnosed with dementia during COVID-19 and are now met with no services or supports. This includes younger people with a different set of responsibilities such as mortgages and young children.
- Family carers are seeing an alarming decline in the person with dementia as a result of COVID-19 restrictions. This is made worse by the fact that medical reviews and interventions are currently unavailable or only take place over the phone.
- Carers are struggling to contact health care professionals in order to access services which adds to their stress.
- There is an 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 use dementia services are now seeking these services. As a result, there will be a large increase in demand once services reopen.

*“Carer concerns prior to lockdown have now quadrupled” (Dementia Adviser)*

## **Our Recommendations**

1. Dementia-specific supports and services must reopen without delay. Guidelines and a clear roadmap from the HSE are required.
2. Dementia should be considered alongside other chronic diseases in planning and managing COVID-19 guidelines and service re-opening. We need more data on dementia and COVID-19. Dementia needs to be considered in public messaging.
3. Public policy should focus on supporting family carers who have been deeply affected during this global pandemic. Support for carers need to be put in place immediately e.g. crisis prevention care and therapeutic services.
4. Planning and investment is essential to meet an increase in demand for dementia services (health and social) once they reopen.
5. Before COVID-19 there was a serious shortage of home care for people with dementia. We need in-home support that focuses on the specific needs of the person (rather than 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 who would provide this service.

## **Conclusion**

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.

COVID-19 has not caused this plight. Instead, it has brought into sharp focus how people with dementia and their carers are routinely neglected and overlooked.

In our first COVID-19 Report published in early April, some carers were fearful that they and their loved ones with dementia would be forgotten. This fear has been realised as they have been invisible throughout this pandemic.

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.

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 enough to address the new and increased needs faced by those living with dementia.

Face to face services must be reopened, re-imagined and re-developed in order to respond to the challenges experienced by people living with dementia and their family carers. Their right to care and the provision of adequate and appropriate care must be paramount now.

## **Acknowledgements**

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