Caring and Coping with Dementia During COVID-19:

Experiences of People living with Dementia and Family Carers

Plain Language Summary

Background

The COVID-19 pandemic has been especially difficult for people living with dementia and their families. Essential Alzheimer Society of Ireland services were suspended in March 2020 including its 48 Day Centres, Social Clubs, Alzheimer Cafes and Support Groups. HSE day centres and respite facilities also closed in an effort to prevent the spread of COVID-19.

Last year, The Alzheimer Society of Ireland published two reports about dementia and COVID-19. The reports detailed how 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
- Exhaustion, stress and burnout
- Boredom
- A lack of support

This is the third report published by The Alzheimer Society of Ireland about dementia and COVID-19.

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Research Aims

1. To explore the impact of COVID-19 on people with dementia and their families one year after the country first locked down.
2. To explore the experiences and needs of people affected by dementia, and how, if at all, these have changed over the past year.

What we did

- Telephone and online surveys with 17 people living with dementia and 240 family carers
- Focus Groups with 9 Dementia Advisers and 6 front-line service managers.
- This research took place between February and March 2021.

What we found

The health and wellbeing of people living with dementia and family carers has shown a clear decline over the pandemic. There is a deep sense of anger and frustration. People living with dementia and family carers feel abandoned and forgotten. This was made worse when family carers were not prioritised for the COVID-19 vaccine.

Impact of COVID-19 on People living with dementia

- Worsening symptoms of dementia (due to lack of stimulation and no services). In fact, 81% of family carers who took the survey feel concerned about a decline in their family member with dementia.
- Loneliness, isolation and boredom.
- A lack of routine leading to anxiety and confusion.
- Social withdrawal and apathy – many people with dementia no longer show interest in re-entering the community or return to their pre-COVID lives.
- Some family carers are considering long term care for their loved one sooner than expected due to COVID-19.
- Those newly diagnosed have been unable to access follow up care or support.

Impact of COVID-19 on Family Carers

- 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.
- Exhaustion and burnout due to caring alongside work and looking after young families.
- Guilt and frustration – feeling like they are not doing enough.
- Grief and Loss – seeing their loved one's dementia decline and feeling powerless.
- Rising tension – 44% of family carers report feeling less able to cope as the time passes.

Supports and Services

Participants noted their appreciation of The Alzheimer Society of Ireland services (e.g. Dementia Advisors, Day Care at Home) but felt there was a general lack of services or that services were hard to come by. Most participants keenly await the return of day care centres.

Greatest Challenges

Reported by Family Carers

1. Needing a break/respite due to exhaustion and burnout
2. Loneliness and social isolation
3. Anxiety and stress related to the increase in caring workload and other responsibilities (e.g. work, young children)

Reported by People with Dementia

1. A lack of routine leading to anxiety and confusion
2. Difficulty in carrying out daily activities (e.g. shopping, taking medication etc.)
3. Fear of COVID-19
4. Isolation and loneliness
5. Feeling down and sad

Supports Needed

People living with dementia value the help and support provided to them by family, friends and health and social care services. Many would also welcome,

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

70% of family carers report needing practical support while 51% report needing emotional support. Examples include:

- 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.

What's Next?

Using this research, we have created practice and policy recommendations. These are similar to last year's report and should be acted on urgently.

1 Reopening of face-to-face services and supports, in particular, Day Centres and support for family carers needs to be explored urgently.

2 People with dementia have unique and complex needs. Dementia should be considered alongside other chronic diseases in planning and managing COVID-19 guidelines and service re-opening.

3 Family carers have been deeply impacted by the demands of caring and their physical and mental health has suffered. There is an urgent need to provide support for family carers (e.g.respite services, crisis prevention care, counselling etc).

4 There will be increased demand on services when they reopen. Planning and investment is needed to meet this demand. More person-centred services aimed at those in later stages of dementia are required (e.g. Day Care at Home).

5 Home Care with attention on social needs requires more resources and funding. The statutory home care scheme should be tested and developed without further delay.

6 No county in Ireland has a minimum standard of services, as identified in a 2018 service mapping report by The Alzheimer Society of Ireland. Investment and planning of dementia services is urgent and must be prioritised immediately. The National Dementia Strategy should be fully implemented, and there needs to be a strong commitment from the Government to do this.

Conclusion

This research took place approximately one year after day services closed. It has highlighted the devastating reality of caring and coping with dementia in COVID-19.

The impact of the ongoing closure has meant feelings of exhaustion, grief and helplessness are common among family carers. They feel their health and quality of life have deteriorated in the past year as they juggle caring and work roles. Family carers report feelings of burnout and despair with no respite or break from their responsibilities. The frustration and anger among family carers is clear with some pleading for recognition; *"Please walk in my shoes. And value me."*

For people living with dementia the lack of stimulation (usually provided in a Day Centre) has caused a noticeable decline in their abilities, according to family carers. Several have lost interest in returning to their usual hobbies and communities. Participants with dementia report feeling lonely and isolated. The lack of routine means they are becoming more anxious and confused and struggle with day to day tasks and activities.

In both previous 2020 COVID-19 research reports, The Alzheimer Society of Ireland provided clear recommendations to improve the situation. It is deeply disappointing that these have not been acted on. This report repeats most of those recommendations.

During COVID-19 limited dementia services have been further reduced, leaving many families in crisis. While online and remote services are helpful, they are not enough to address the new and increased needs faced by those living with dementia. Face to face services must be re-designed and re-developed to respond to the pre-Covid and post-Covid challenges for those living with dementia and their family carers. Adequate care and service provision is critical and must be addressed immediately.

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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.

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