



DementiaUK

Helping families face dementia

Impact of COVID-19 – summary report of carers’ experiences

September 2020

Background

Between August and September 2020 we circulated a survey to assess the impact COVID-19 has had on families affected by dementia.

The survey was circulated via Dementia UK's: Campaigns Network eNews, General Dementia UK eNews, Corporate Partners, Volunteer Ambassadors, Dementia UK fundraiser Facebook page, Dementia UK Twitter and LinkedIn pages. The survey link was also available on the Dementia UK website (campaigns page).

169 family carers responded to our survey

- 88% were female
- 40% were daughters and 33% were the wife of the person living with dementia
- 89% were white-British
- 64% were under 65 years old

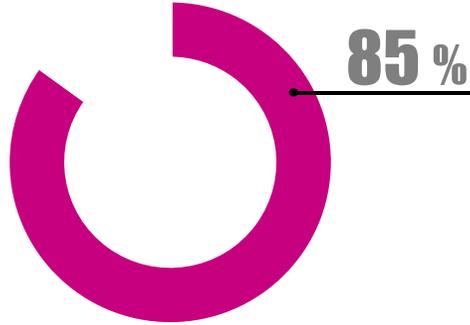
This report provides a summary of the experiences shared by those family carers, key findings include:

- **Loneliness & isolation:** families struggling with loneliness and social isolation since COVID-19
- **Wellbeing:** a deterioration in the wellbeing of person living with dementia during this period, and carers struggling with their own wellbeing
- **Access to support:** families experiencing a lack of care and support during this time

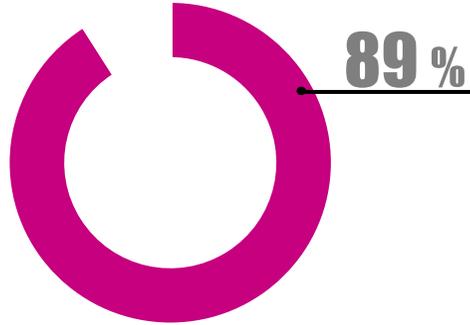
Acknowledgements

This report would not have been possible without the contribution made by the family carers who responded to our survey. We would like to thank them for their time and for sharing their experiences highlighting the impact of COVID-19 on them and their families.

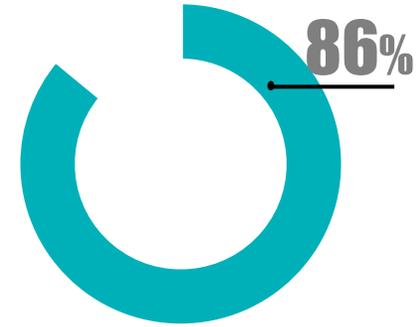
Summary of carers' experience since the start of the covid pandemic



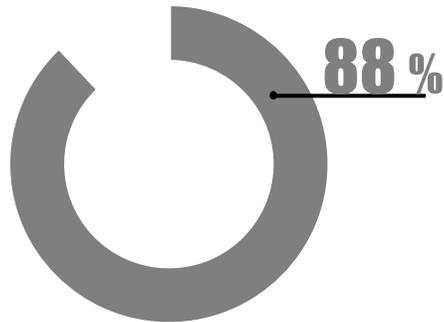
...of carers felt **lonely**



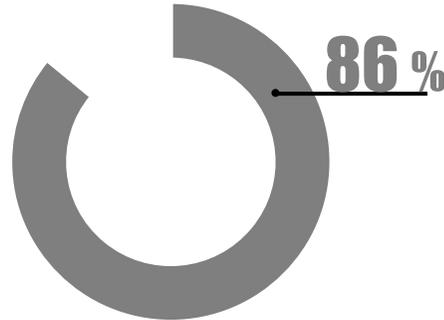
...of carers felt **isolated**



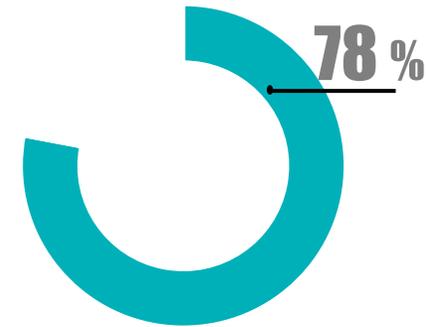
... of carers said that there had been a **negative impact on their own wellbeing**



... of carers hadn't been able to access **all** the care and support services **they need**



... of carers hadn't been able to access **all** the care and support services **the person living with dementia needs**



... of carers said that there had been a **negative impact on the wellbeing of the person living with dementia**

Loneliness and isolation

The COVID-19 restrictions have had an effect on feelings of loneliness and isolation among carers. Since the COVID-19 restrictions were put in place :

- **85%** (n=144) of carers said that they felt **lonely** (some, most or all the time).
- **89%** (n=150) of carers said that they felt **isolated** (some, most or all the time).
- **83%** (n=126) said that they had less opportunities to take a break from caring.
- **74%** (n=114) said that the amount of time they provide care for increased.

"I've been very affected with lack of contact with friends and family I feel lonely and as though no-one cares."

73 years old, wife of the person living with dementia

"The lack of social interaction via the Dementia Cafes had a marked effect on both myself and my wife who has Alzheimer's."

88 years old, husband of the person living with dementia

"I've felt isolated whilst looking after my mum. Working from home and looking after her felt I was trapped within the same walls everyday. Made me feel lonely and very down."

59 years old, daughter of the person living with dementia

"The isolation and loneliness took its toll almost immediately. My mother started to refuse to eat / drink. She went from outgoing to depressed and died within weeks. She literally starved and dehydrated to death."

53 years old, daughter of the person living with dementia

Wellbeing

Caring for someone with dementia can be rewarding, but it can also have negative consequences for family carers' health and wellbeing.

We asked carers to think about their life as a carer since the start of the COVID-19 outbreak and whether this period had an impact on their wellbeing, as well as the wellbeing of the person living with dementia.

- **86%** (n=144) of carers said that there had been a negative impact on their own wellbeing (physical, mental and social wellbeing) since the COVID-19 outbreak.
- **78%** (n=129) of carers said that there had been a negative impact on the wellbeing of the person living with dementia (physical, mental and social wellbeing) since the COVID-19 outbreak.

"I am finding life very distressing at present as I can't see things getting back to normal for the foreseeable future and I don't know what to do about leaving mum in the care home as I may not get to see her but I don't feel I can cope with looking after her at home because of the lack of support available, and my partner has Parkinson's and also requires care from me."

43 years old, daughter of the person living with dementia

"The worry and concern about my mother's deteriorating mental health and lack of any meaningful physical contact with a relation has had a very bad effect on my own mental health. I am stressed and depressed and have many sleepless nights."

daughter of the person living with dementia

"My husband declined rapidly, not able to understand why we could not go out or why his family could not come near us. He became increasingly confused and agitated...his balance worsened, he had difficulty in communicating his needs and became angry. he lost interest in everything, I had to cope alone as we could not have contact with others, only by phone. It became so difficult and heartbreaking to watch." 78 years old, wife of person living with dementia

Access to support

The COVID-19 restrictions have had an impact on carers access to care and support services, as well as on the access to services that the person living with dementia needs.

- **88%** (n=128) of respondents hadn't been able to access **all** of the care and support services that they need since the COVID-19 restrictions were put in place.
- **86%** (n=137) of respondents hadn't been able to access **all** of the care and support services that the person living with dementia needs since the COVID-19 restrictions were put in place.
- **71%** (n=82) said that home visits from care and support staff had been cancelled (either by themselves or by the service) since the COVID-19 restrictions were put in place.

"As the dementia has been picked up and diagnosed during Covid lockdown, not being able to access services - at all in some cases and only on the phone in others, it has been very difficult and entirely reliant on the presentation of symptoms as relayed by my husband and I, it would have been / be good to have an independent and medical direct viewpoint. Services have been slower to respond and there has been a lack of clarity about what is available..."

38 years old, daughter in law of the person living with dementia

"I feel that we've been forgotten by the GP and social services. I think it will not be back to normal for a long time. I don't think that I will be able to look after my husband much longer without help unless the day centres open again and I can get some time to myself."

73 years old, wife of the person living with dementia

"I have felt largely abandoned by the nhs during lockdown where my mothers health is concerned. I have been left to make clinical decisions which I shouldn't have to make ..."

59 years old, daughter of the person living with dementia

Access to support

- All of those (n=132) who had tried to make an appointment with their GP were offered appointments - **88% were offered telephone or online appointment(s)** and 12% were offered face to face appointments.
- However, **nearly half** (48%, n=53) of those offered telephone or online appointment, said that **this type of support didn't meet their / the person living with dementia's needs.**

"Telephone appts are difficult when I am talking about my mother, the doctors cannot see her and assess her colour, mood etc because of her dementia she tells them she feels fine but ... this has not been the case. We had one video call but again a doctor looking at my mum's chest via video is not good enough a system to accurately determine her respiratory rate although the doctor did her best."

59 years old, daughter of the person living with dementia

"My father experienced a bout of delirium and the GP said he would phone back in 24 hours to assess. It worsened overnight and my father had a traumatic fall and was found hours later and subsequently admitted to hospital."

53 years old, daughter of the person living with dementia

"These type of appointments caused friction between me and my husband for whom I care because we had to use my mobile phone on speaker and he doesn't understand how this works ..and got very agitated/resentful with me. I was exhausted after all of these calls."

72 years old, wife of person living with dementia



If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org
Open Monday – Friday, 9am –
9pm Saturday and Sunday, 9am –
5pm

@DementiaUK • www.dementiauk.org

Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).