



DementiaUK

Helping families face dementia

Dementia UK digital survey

June 2021

Acknowledgements

This report would not have been possible without the contribution made by those who responded to our survey. We would like to thank them for their time and for sharing their experiences and views on digital services.

Dementia UK Digital Survey

In March 2021 we circulated a survey asking people about their experiences of accessing dementia information, care or support services digitally since the start of the coronavirus pandemic. The survey also collected information to help develop and improve the digital services offered by Dementia UK to best meet the needs of people living with dementia and their families, friends or supporters in the future.

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).

137 people took part in our survey, sharing their experiences and views on:

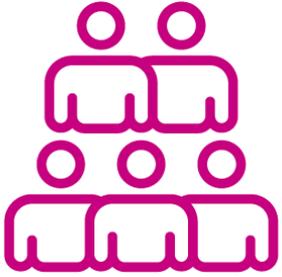
- Using digital technology
- Using digital services for dementia information, care or support
- Using Dementia UK's digital services



This report summarises their experiences and views - results are presented for the sample as a whole and also highlights any areas where responses from those living with dementia* differed from the larger sample.

Who took part in our survey?

137 people responded to our survey:



- Around three quarters were carers, family members or supporters of someone who has or may have dementia
- 17 were people living with dementia
- 15 said 'other' (including people who had previously been caring for a person with dementia, people concerned about their own memory)

Carers, family members, supporters and 'other' (n=120)

- Over three quarters were female (78%) and aged between 51 and 80 years old (76%).
- Just over half (56%) were looking after or helping a person who had been diagnosed with dementia aged 65 or older
- 40% said the person had been diagnosed before the age of 65
- Just under three quarters said the person with dementia was living at home - either with them (49%), with others (15%) or living at home alone (9%)

People living with dementia (n=17)

- Respondents were fairly equally split between male (9) and female (7)
- Almost all were aged between 51 and 70 years old (15)
- Most had been diagnosed with dementia before the age of 65 (12)
- Almost all were living at home - either with family (10) or living alone (6)

Using digital technology



Using digital technology

- Almost all respondents were using digital technology every day (96%).
- People were using a variety of digital technology devices - mobile/smartphone (88%), computer/laptop (72%), tablet (60%).
- Around a quarter said there were barriers which limited or prevented them using digital technology, including: 'lack of confidence'; 'a physical, hearing or sight disability'; and 'poor internet connection'.

People living with dementia were more likely to report barriers which limited or prevented them using digital technology – with more than half saying there were barriers.

Using digital technology for health

- Three quarters of those responding were confident using digital technology for health and knew how to access this.

People living with dementia were less confident about using digital technology for health – just over half said they were confident.

- Two thirds said that they wanted to use digital technology for health (68%), however, just over a third had concerns about the privacy or security of their information (37% of respondents said this).

People living with dementia were more likely to say they wanted to use digital technology for health – with three quarters saying this.

Using digital services for dementia information, care or support

- Most respondents (94%) had used digital services to access dementia information, care or support since the start of the coronavirus pandemic and would continue to use when the pandemic was under control – top two reasons for using were to find information (86%) or seek advice about dementia (65%).

Two thirds of people living with dementia had also used digital services to find emotional support.

- People were most likely to continue or start using these services if it made their life easier - 82% said this. A significant minority (43%) also said they would use these services if they could guarantee their information was safe.

Around two fifths of people living with dementia also said 'if I could access at home' and 'if my clinician/trusted person recommended to me'.

- When asked what was good about using digital services, the most common reasons were: 'it saves time' (70%); 'it happens at a time I choose' (56%); and 'it is easier to share information' (43%).

Three quarters of people living with dementia also commented that digital services helped them manage their condition and over half said it improved communication with health professionals and it was good because they can choose who they see.

Using Dementia UK digital services

To help us shape the digital services offered by Dementia UK we asked respondents whether they had used any of Dementia UK's digital services, most had used one or more of the current range of services on offer (81%) – almost all had accessed information from the Dementia UK website.

We also asked people whether they would be interested in using a range of Dementia UK digital services in the future - slightly more said that they would be interested in doing this (88%).

In addition to accessing information from the Dementia UK website, our respondents would be interested in using a range of digital services:

- Just over half would be interested in contacting the Dementia UK Helpline for advice or support
- Over 40% would like to attend an online information and advice session with an Admiral Nurse, access resources specifically about young onset dementia, contribute to, read or share Dementia UK e-news or social media activities
- Over one third would like to attend an online support group with an Admiral Nurse or use online 'chat' for advice
- Over a quarter would like to attend a video clinic with an Admiral Nurse, take part in an online social group or use interactive online information resources

Some carers added comments about the services they would like:

"It would be good to have sessions online so that they could see Mum."

"May like to try the on line support group"

"Make it more localised".

"Local-specific information would be good"

Using Dementia UK digital services

All people living with dementia said they were interested in using a range of Dementia UK digital services in the future.

15 people living with dementia told us about services they would be interested in using. More than half said:

- accessing resources specifically about young onset dementia, contacting the Dementia UK Helpline for advice or support, contributing to, reading or sharing Dementia UK e-news (10)
- taking part in an online social group; using interactive online information resources; contributing to, reading or sharing Dementia UK social media activities (8)

Some people living with dementia added comments about the services they would like:

“Probably - I dream of having a service tailored to my needs: I have failing verbal but good visual memory. But virtually all online services are text based and don't use visual cues much. I suggest that decent digital services for people with neuro degeneration should be able to be adjusted to take into account individual differences in cognition.”

“A list of who does what. What can one expect? Tutorials for commissioners of services...Assistive tech for all with training..”

“Easy to access tech support & frequently asked questions”

“Peer support groups for people living with dementia, and peer support groups for carers.”



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).