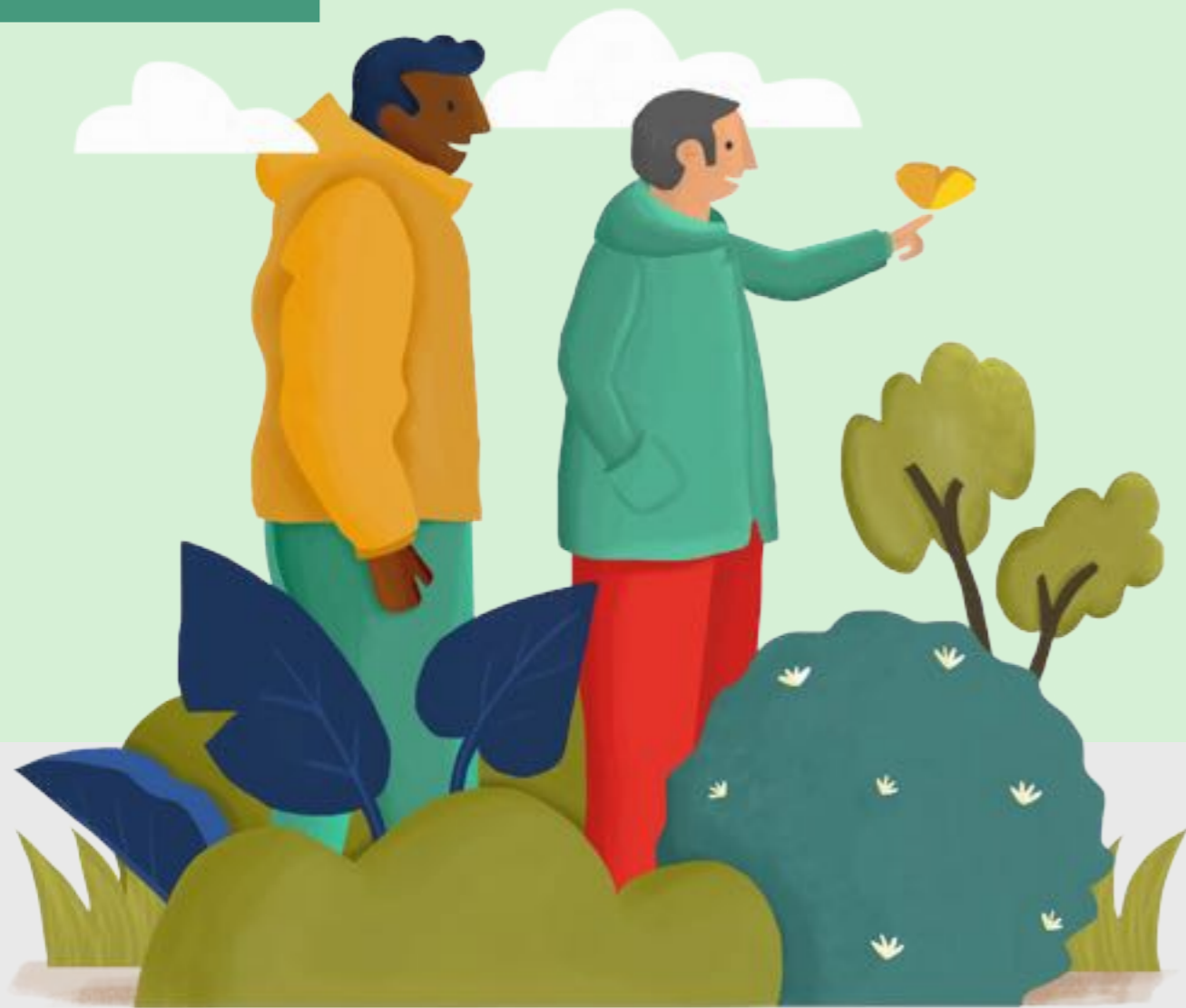


# Portraits of CARE



## Research Summary Report: UK



UNIVERSITY OF  
WESTMINSTER



## What is the purpose of this research?

The Portraits of Care study was designed to understand more about what it is like to care for someone living with Alzheimer's disease.

The researchers used both surveys and interviews with informal caregivers (a term which means people who are not being paid to care for someone) in four countries: **United Kingdom (UK), United States (US), South Africa and Brazil.** These four countries highlight the diversity of healthcare systems, cultures and average income for households.

The study was carried out by researchers at the University of Westminster (based in London, UK), in partnership with Alzheimer's Disease International (ADI) and Roche. Roche provided funding and, alongside ADI, took part in the development and design of the study. In the UK, the study was supported by the Alzheimer's Society who helped communicate information about the study to people who might want to take part.



*This summary describes the findings from the Portraits of Care research in the UK. We want to thank everyone who took part, and especially thank the people who shared their photographs and personal experiences with us. It was a real privilege to hear these stories. We know that participating in research takes time, and finding time is difficult when you have a caring role, we are grateful for your help in being able to tell more people about these experiences. We want to thank the Alzheimer's Society for supporting our recruitment with a listing on Join Dementia Research.*

## How did the researchers collect information?

There were two parts to this study.

**The first part was a series of questions in an online survey.** Caregivers' answers helped the researchers to understand more about the experience of caring for a loved one with dementia, particularly during the COVID-19 pandemic. Questions caregivers were asked included how caregiving impacted their mental health and wellbeing, the extent to which they experienced symptoms of depression and anxiety and felt lonely, and how much of their time and effort is taken up by caregiving. **In the second part of the study, a smaller number of caregivers in each country who completed the survey took part in interviews about their experiences.** Photo elicitation – a research method which involves participants taking photos of meaningful objects or places and discussing these during interviews was used in this part of the study.

## What happens now?

The study partners hope that findings from Portraits of Care will help to strengthen Alzheimer advocacy efforts and guide improvements to carer support services.

By sharing care-giver experiences more widely we hope that people will learn more about what it's like to be a care-giver for someone living with Alzheimer's disease. Maybe these insights will inspire others to think about how they might be able to offer support or resources from a personal or professional perspective.



## Who took part?



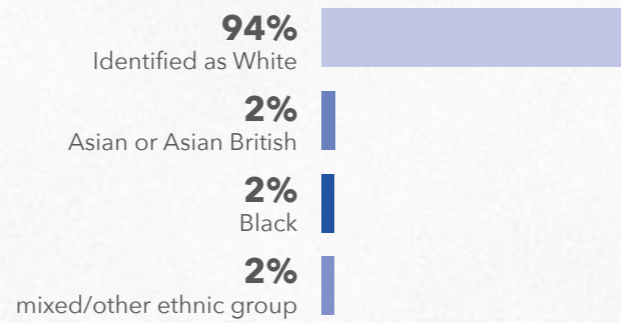
**In the UK**, 127 caregivers completed the online survey\* and of these respondents, 10 took part in in-depth interviews.

Among the survey participants:

### Gender:



### Ethnicity:

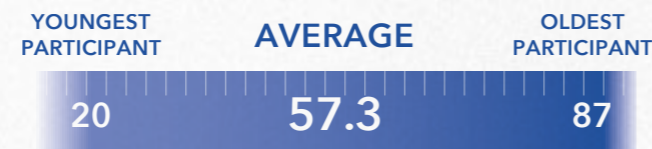


The study partners and local organisations aimed to recruit as diverse a sample of participants as possible to take part in Portraits of Care. However we recognise that despite best efforts our sample is not as representative as we would have liked. We acknowledge there is more to do to encourage participation in dementia research.

### Employment:



### Age:



### Health:

**72%** of caregivers rated themselves to be in **good, very good, or excellent** overall health

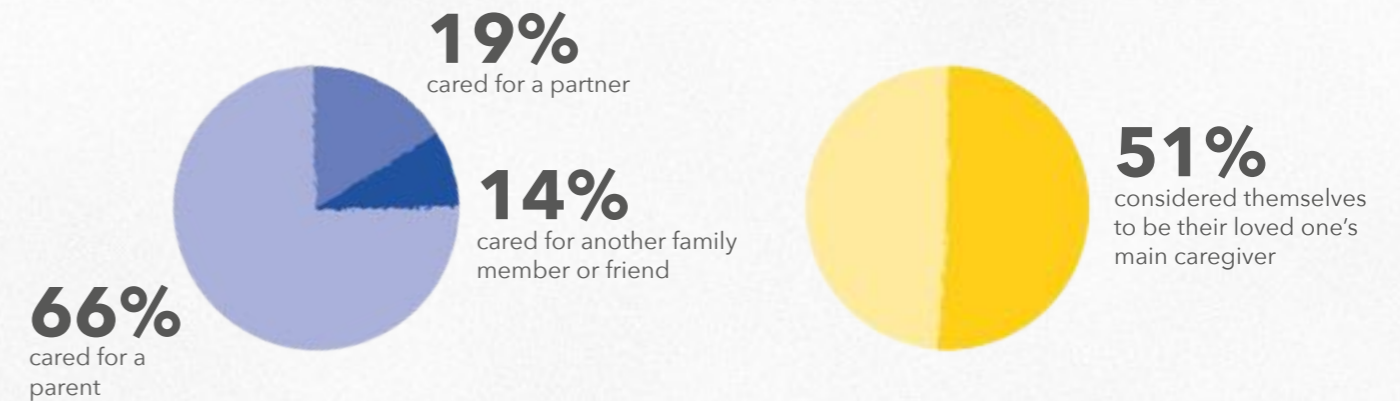


\*Please note that some participants chose not to answer every question within the survey.

## Who did they care for?

Caregivers shared information about the people they cared for:

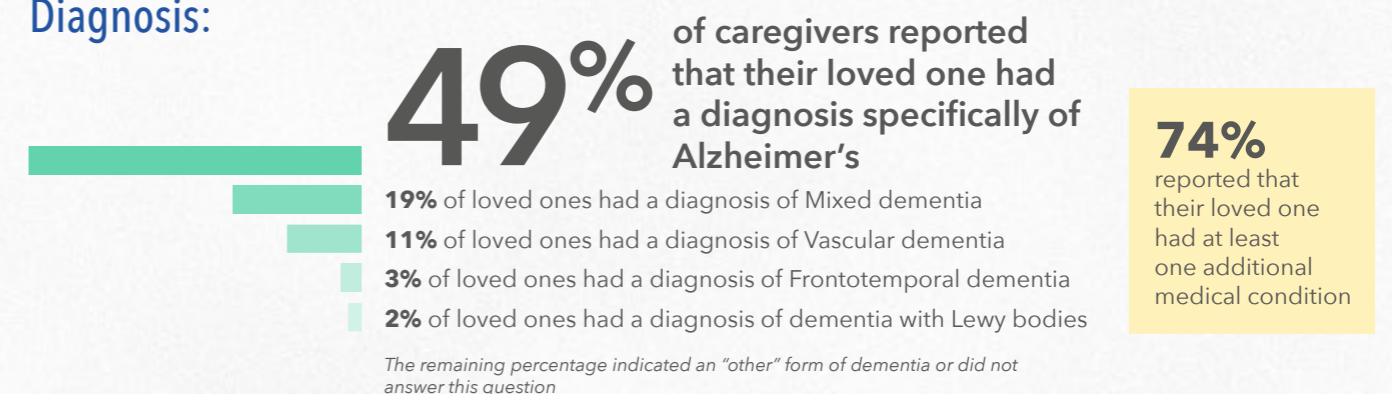
### Carer relationship:



### Severity:

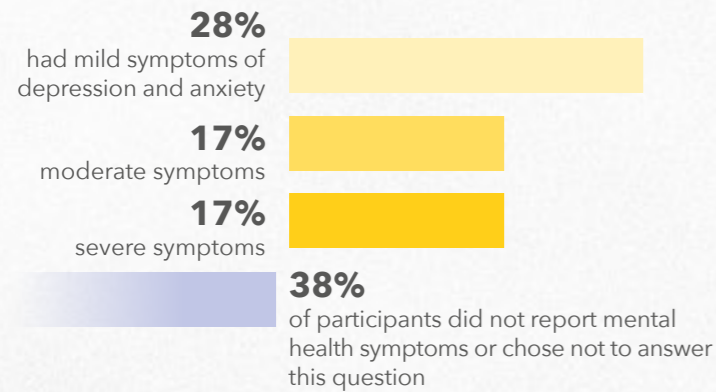
About **45%** of caregivers said that their loved one could not function independently or be taken outside the home because of their dementia

### Diagnosis:



# What were the impacts of caregiving?

## Mental health:



## Poorer mental health was linked to:

- Lower perceived community standing (how they saw themselves in relation to others in their community)
- Being a younger caregiver

## Loneliness:

Participants were asked about the extent to which they felt they lacked companionship, felt left out, or felt isolated from others.

On average, participants in the UK were found to be on the borderline of loneliness (based on how they responded to the survey questions).

## Increased loneliness was linked to:

- Caregiving for a greater number of hours per week
- Lower perceived community standing

## Caregiver burden:

Caregivers also shared information about how much time and effort was taken up by their caregiving role: the extent to which the person they care for is dependent on them and needs their help with day-to-day tasks.

## Higher caregiver burden was linked to:

- Caregiving for a greater number of hours per week
- A higher severity of dementia in the person they cared for

## Employment changes:

# 70%

reported changes to their working status since taking on their caregiving role, in which:

- 20% had to stop working altogether
- 17% had to reduce their working hours
- 3% had to change their job
- 28% reported other additional impacts (including needing to take unpaid time off, and affecting perceived quality of work)

## Interview Insights

The practical demands of caregiving impacted on time available for caregivers to engage in their own self-care and leisure activities as well as having strong emotional impacts for some (e.g., difficulties seeing a parent in a more vulnerable position).

Having good support in place was integral to reducing the negative emotional impacts for several caregivers.

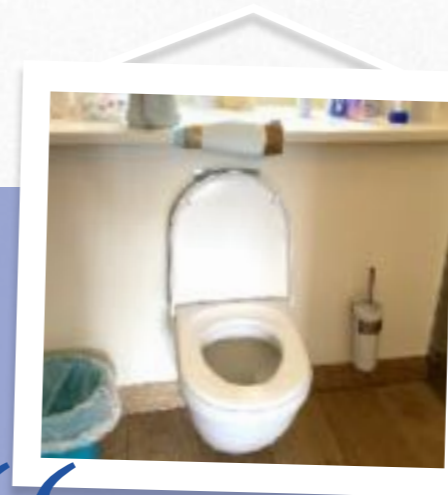
“

I had lots and lots of interests, which I've now, of course cut out. I mean they come, they come second, if you like, and, and my wife is, is number one...I'm a potter, sculptor, woodworker...I love music and played music and that sort of thing. And all those have gone by the board. But that doesn't matter. I can, I can live, live with that”

(George, M, 87, caring for his wife)



Participant image of music stand and wood carving



“

there's a lot of toiletry stuff – and that's why that was kind of put in

(Nasrine, F, 52, caring for her mother)

“

I felt very dark and black, and then luckily my daughter had 10 minutes or something to...you know, half an hour, she could pop in...we had a laugh and a cup of coffee and then I suddenly realised my mood had gone up from one or two, up to about three or four or even five.”

(George, M, 87, caring for his wife)

## How satisfied were caregivers with the support they received?

Caregivers rated how satisfied they felt with support they received from the following sources for their caring role:

- Family
- Friends
- Local community
- Support groups (carer groups, Alzheimer's charity groups, and online groups)
- Healthcare services
- practical/physical support (for example paid carers within the home).

### Satisfaction ratings were:



Highest for support from family



And lower for support from support groups and the local community

### However, many caregivers did not use formal support groups at all:



**48%** didn't access carer groups



**52%** did not access Alzheimer charity organized groups



And **62%** did not access online support groups

## Interview Insights

During interviews, many frustrations were expressed with inconsistency and unreliability of practical and physical support in particular for caregivers in the UK, often in relation to paid care. Issues included paid carers not fulfilling their roles properly, not being suitable for the person with dementia (e.g., unable to communicate with them effectively due to language barriers), and a high turnover of carers from care companies, which could lead to confusion for people living with Alzheimer's and increased stress for their informal caregivers.



if you're caring for somebody, you've got to give them time... they're sitting on a toilet and can't go to the loo, they need time to go to the loo. It's not good saying, "Well, me half hour's up, that's it, back into your soiled pants and you can sit there all day." Um, and of course, the care, the care system doesn't allow that."

(Kirk, M, 68, caring for his mother)



it's great, they're great, they're actually fantastic girls...And so my mother, I feel safe that they're, they're great. And one of the things though is a high turnover...In that industry. Um, and that, that's hard for somebody with dementia."

(Amanda, F, 52, caring for her mother)

In interviews, caregivers were also asked about more general support from charities. Responses highlighted that there was often ambiguity around how charities could support them, in addition to some practical difficulties accessing and navigating this type of support. Generally, charities in the UK were also perceived as more research-focussed rather than a strong source of practical support for caregivers.



**None whatsoever [contact with Alzheimer's Society] I don't know what I would say to them...I'm a bit out of my depth, I'll be perfectly honest, I am a little bit out of my depth..."**

(George, M, 87, caring for his wife)



No, I didn't contact them (Alzheimer's Society) at all...I should have done. Like I said, I was just sort of trying to desperately find a more immediate solution which was: financial help and the second thing was find the right carers. Those were the two main focuses of mine. And so no I didn't."

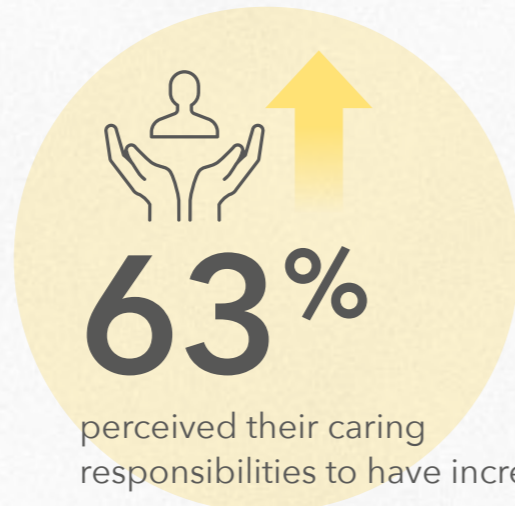
(Nasrine, F, 52, caring for her mother)

# How did the COVID-19 pandemic impact caregivers?

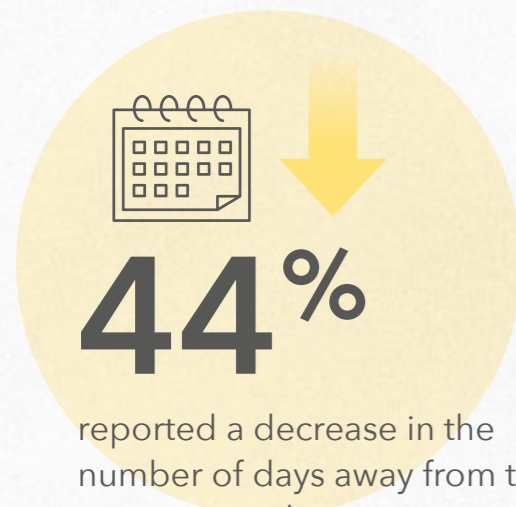
Participants reflected on how they felt the COVID-19 pandemic affected their caregiving role and access to both practical support and support for their own wellbeing.



reported an increase in the number of hours per week they spent caregiving



perceived their caring responsibilities to have increased



reported a decrease in the number of days away from their caregiving role



experienced decreased opportunities for self-care e.g., cooking healthy meals or exercising



When asked about access to support throughout the pandemic, caregivers reported impacts on both accessibility of different sources of support during this time, and the mediums by which support was received.

All support systems were disrupted in some way for at least some caregivers, whilst only a minority experienced increased access to support during this time.

## Interview Insights

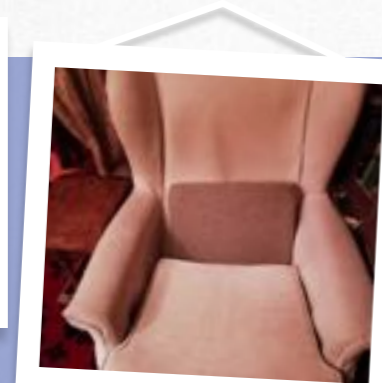
Interviews revealed differing experiences during the pandemic, for example with the extent to which access to usual support and day-to-day experiences were affected.

This affected the way in which caregivers in the UK viewed the impact that this time had on them and their loved ones.



...all the people who I have relied on closely, me brother and me best friend and stuff were no longer around, they weren't visiting...there was no, you know, no support, I was on me own. That was a symbol of many things, it was empty...all the people who I was on me own. So, 24/7 chair empty"

(Kirk, M, 68, caring for his mother)



...the pandemic actually was good for me because it really helped me to kind of step back"

(Nasrine, F, 52, caring for her mother)



...The previous home she was in was really good with communication. Um, so a lot of newsletters, updates...so they were brilliant, um, and then engaging through, uh, FaceTime...So the home was fantastic doing that."

(Charlie, F, 48, caring for her mother)



Some caregivers spoke about their experiences with having their loved ones in a care home in the UK during the pandemic. Care homes were affected by the restrictions significantly, and interviews revealed differences in how well they adapted to this and how this impacted the experience of caregiving for a loved one who was in a home in 2020/2021.

Caregivers also talked about the fear of COVID-19, how the infection risk was a threatening presence.



So there was food in there that I, that I kept, that had long life. So to, for me it was, I know I'm not going to run out of food and food that they like, because I can't get it in the shops and I don't go out. And so I took the decision, I never went out."

(Angelina, F, 59, caring for her parent)



## What would make the caregiving role easier?

In the survey, participants gave insight into what things they felt would make caring for their loved one easier for them.



84%

felt more practical support would be helpful



75%

more emotional support



70%

more breaks from their caregiving role



63%

more financial support



52%

more information and classes about Alzheimer's

## Interview Insights

“

*...Me and my carer who I found at the beginning of the pandemic, were kind of doing this together but she needed a break...and 'I' needed a break so we thought we 'have' to get a second carer...and the costs were just, you know getting crazy, like, spiralling out of control.”*

(Nasrine, F, 52, caring for her mother)

“

*Someone to just come and give me a break”*

“

**that's the problem. I don't know what support I need or what support is available.”**

(Tedcu, M, 73, caring for his partner)

“

**And as soon as she broke her leg, the NHS provided a commode and the reclining wheelchair and a transfer machine.”**

(Curly, M, 87, caring for his partner)

