



# Carers' views of residential respite for their relatives living with dementia beyond the COVID-19 pandemic: is it worth it?

Kritika Samsi, Katharine Orellana, Laura Cole, Jill Manthorpe

# Residential respite (short stay in a care home)



Respite aims to provide a break for family carers and for the person being cared for

Carers more likely to take up respite services if they see them as mutually beneficial to both them *and* their relative with dementia

➤ hence terms 'short breaks' or 'restorative care'

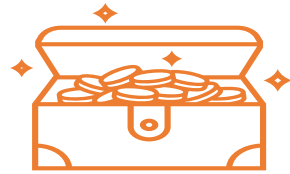
**\*\* A greater understanding of residential respite use was needed \*\***

➤ Why some people use it

➤ Why some people don't

➤ Barriers to accessing it

# Study details

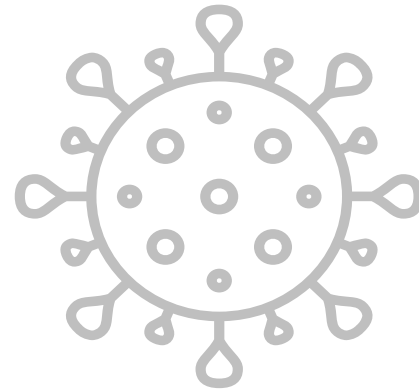


2 year study

February 1<sup>st</sup> 2019 –  
January 31<sup>st</sup> 2021

We asked  
people living  
with dementia  
and  
their carers  
about  
residential  
respite

**Experiences  
and  
expectations**



**Access**

**Outcomes**



15 carers  
who  
**had used /  
experienced**  
respite

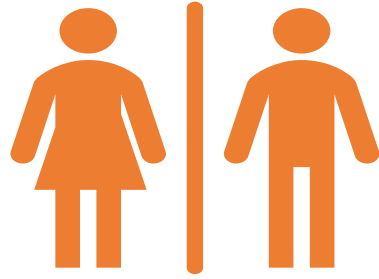
4 carers  
**awaiting**  
**respite for**  
**the first time**



17 carers  
who **had**  
**declined**  
respite

**7 people**  
**living with**  
**dementia**

# Carers' characteristics



30 5



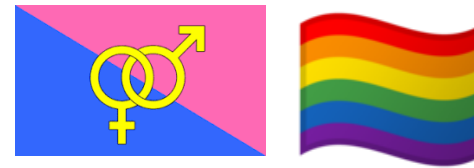
Aged 30-83  
(most 50-79)



15 adult children  
15 spouse/partners  
1 sibling  
4 other family members



30  
White British

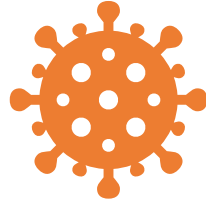


33 heterosexual 2 LGB



29  
owner-occupiers

# Context



- Covid-19 pandemic
- Interviews were not in-person
- Restrictions and infection in care homes
- Community services temporarily closed
- Some services moved online
- Domiciliary services affected
- Greater burden on family carers

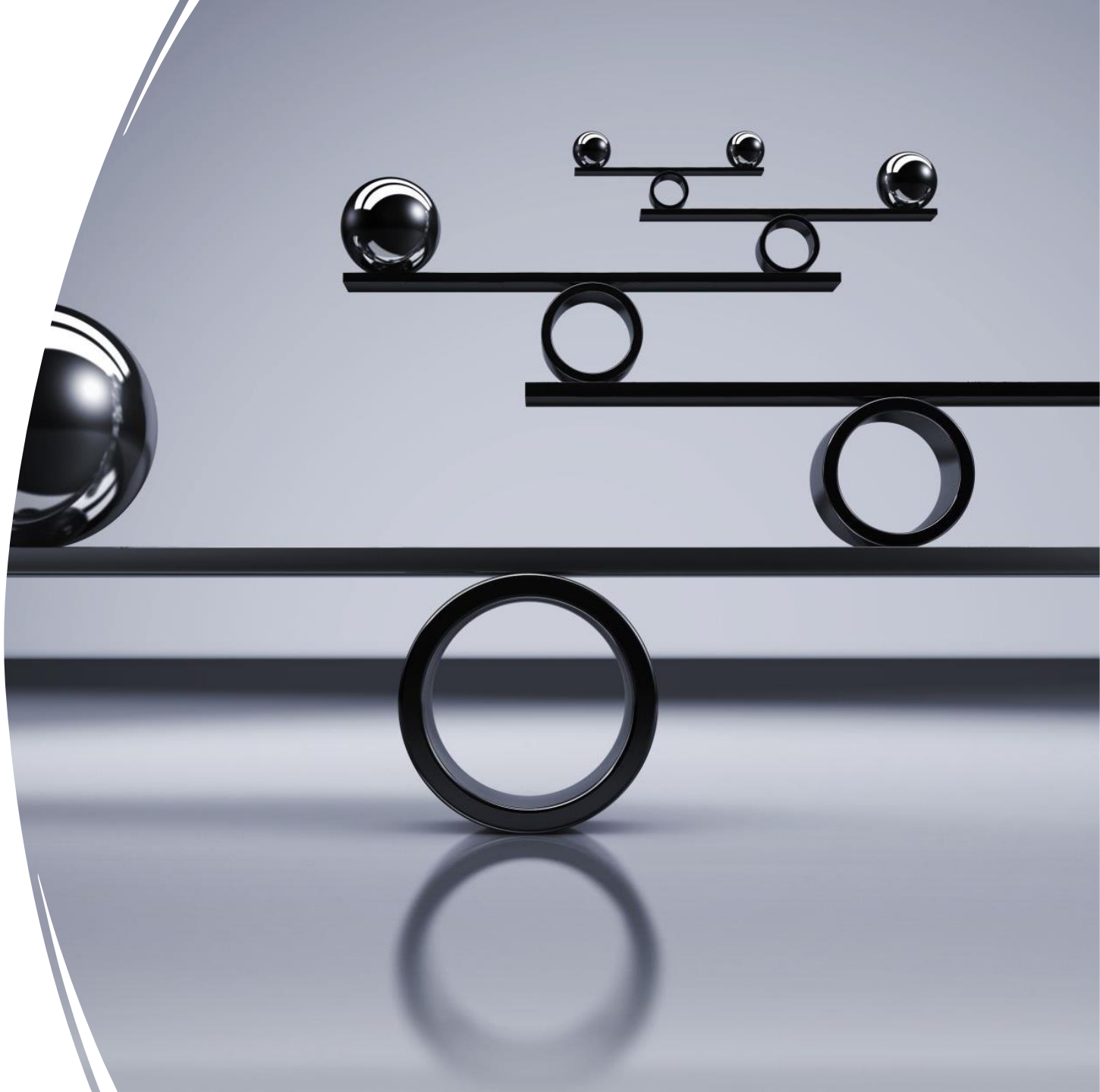
# Three main findings cover

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Negotiating the risks and stresses of Covid

Balancing different needs

Continued uncertainty about future respite and future support in a post-Covid world





## Preventing infection

The worry of it... [my husband] *is very poorly, and I didn't want him even going to the hospital.* I just feel that if you're out of your own little bubble, you become more vulnerable. (...) Respite, day centres, anything like that... even hospital appointments we have done on the phone... He [husband] can go in my car and if I take him somewhere, then I will know 99.9% we're okay.  
*(Carer 06, declined respite)*

# 1. Negotiating the risks and stresses of Covid

Preventing infection

## **Changed family arrangements**

[My daughter] stayed here for a month and all of the girls' employers are aware of our situation. They're very supportive. But at that stage everybody was working from home anyway and they were all told, 'No, you can go and support your family and work from home' in the knowledge that the work from home would be not as active as normally.

*(Carer 09, declined respite)*

# 1. Negotiating the risks and stresses of Covid

## Prioritising relative's needs

I've more or less accepted the fact that the respite is certainly not going to happen for a while, because as I said to you, there's no way I would expect [husband] to go in somewhere and spend a week in his room... There won't be any respite for me or for any of our friends' group, certainly not.

*(Carer 02, awaiting planned respite).*

## 2. Balancing different needs

Prioritising relative's needs

## **Different carer “breaking points”**

*Participant:* It's really going to depend on how I get on with my husband as to whether I feel I get to the point where I really, really, it'd be detrimental to us for me to keep him here [at home].

*Interviewer:* And how have you been coping over the time with Covid and the lockdown that we had?

*Participant:* About the same as everyone else I think. You have good days, you have bad days.  
(*Carer 01, awaiting planned respite*).

## 2. Balancing different needs

Prioritising relative's  
needs

Different carer  
“breaking points”

**Impact of cumulative  
caregiving  
responsibilities**

My brothers are quite concerned that my sister and I kind of have a bit of a burnout and other things are impinging on our care responsibilities (...) So, yes, we have had a discussion and also had the opportunity to visit a couple of people in a couple of care homes locally.

*(Carer 07, declined respite)*

## 2. Balancing different needs

## Availability of residential respite

Some are still not accepting new people, so there is not the availability but, actually, if it's an emergency you're more likely to be. So, I think at the moment, probably for the next six months, it would have to be emergency use for respite only rather than planned respite.

*(Carer 05, had experience of respite)*

3. Continued uncertainty about future respite and future support in a post-Covid world

Availability of residential  
respite

## **Worry about ongoing restrictions in care homes**

I would be concerned if he went in [to a care home] now and he was isolated in a room, you know, and everybody that went in was gowned up, masked up, you know, and took him his food in and all he could do was sit in a chair and have no interaction with anybody because he can't shut up. He likes to talk [laughs].

*(Carer 11, declined respite)*

3. Continued uncertainty about future respite  
and future support in a post-Covid world

Availability of residential  
respite

Worry about ongoing  
restrictions in care homes

## Information sources



3. Continued uncertainty about future respite  
and future support in a post-Covid world



# How do these findings inform practice and policy?

Residential respite is a positive, acceptable option for some carers and people living with dementia who need a break.

Covid-19 has heightened some stressors, and individual confidence to use respite services may need to be rebuilt.

- Professionals could assist in providing practical information, and offer to accompany people on initial visits.
- Peer support groups may also provide advice and suggestions.

Care home providers need to recognise possible heightened anxiety about taking up respite and address individual apprehensions.



## Is it worth it? Carers' views and expectations of residential respite for people living with dementia during and beyond the COVID-19 pandemic

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### Abstract

**Objectives:** The Covid-19 pandemic has taken a heavy toll on many people living with dementia and carers. Caring for a person living with dementia at home with limited avenues for support and a break challenged many carers. Care homes in England closed to visitors, with very few offering opportunities for a short-stay. We investigated impact of Covid-19 on views and expectations of carers of people living with dementia about residential respite.

**Methods/Design:** Qualitative interviews with 35 carers were conducted March–December 2020: 30 women and 5 men, with ages ranging 30–83 years. Interviews explored experiences, views of residential respite, and expectations post-Covid. Data were thematically analysed and salient concepts were drawn out and discussed within the research team and study advisers.

**Results:** Three themes were identified in transcripts, relating to impact of Covid-19 on views and expectations of respite: (1) Carers described regularly *negotiating*

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# Thank you for listening!

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