

"It's like a weight lifted off your shoulder": a qualitative study of adult carers taking a break

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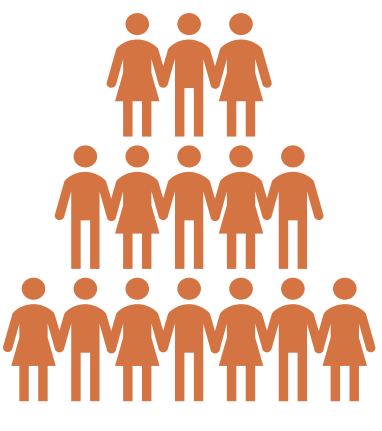


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1 Background

Unpaid carers provide care to ill and disabled family members, friends, partners or neighbours.



5.7 Million
unpaid carers
in the UK
(Carers UK, 2023)

46% of unpaid carers
unable to take a break
in the last 5 years
(Carers UK, 2019)

Caring has a
significant impact on
a carers' health and
wellbeing (Mason et al, 2007)

Respite care supports the cared-for-person but allows the carer to have a break from caring. A break is considered essential for carers to enable them to continue to care (SCIE, 2023).

Understanding how we can best support unpaid carers to care and live meaningful lives is a significant public health concern that needs to be addressed.

RESEARCH QUESTION: What are the experiences of carers of adults in a home setting who have had a recent break (4-14 days) from caring and what impact did it have on their caring role?

2 Methodology

- A phenomenological approach guided 10 one-to-one semi structured interviews with carers (a purposive sample) who'd experienced a break by placing their cared-for-person in a temporary institutional respite service (Leuchie House, National Respite Centre).
- Reflexive thematic analysis following the six steps as advocated by Bruan and Clarke (2022) was undertaken to analyse their experiences of a break and how it impacted on their caring role.

3 Analysis

10 carers participated in this research. This included 6 males and 4 females. Nine of them cared for a partner or spouse, and one for their father. Three were aged 50-59, five were aged 60-69, one was aged 70-79 and one was aged 80-89. Eight cared for people with a primary diagnosis of Multiple Sclerosis, and two cared for people with disabilities resulting from a stroke(s).

Six themes were generated: 'Caring is all-consuming'; 'Caring changes sense of self'; 'Relief, recovery, repair'; 'Breaks give carers their lives back (briefly)'; 'A break doesn't solve everything'; and 'The respite centre is crucial'. Four Key themes are highlighted below:

CARING IS ALL CONSUMING

- Carers have little time for anything but caring, and experience extreme physical and mental exhaustion beyond what is normally acceptable.
- Carers are pushed to the point where they struggle to cope with their caring role.
- The caring relationship is one that is not balanced with the needs of the cared-for-person always coming first.
- Carers cannot simply switch off this responsibility. Caring must go on and it can be relentless.
- The all-consuming nature of caring shows why a carer might need or want a break.

[...] but there are times when I'm like, I don't know how long I can do this for, you know. (Dave)

I've always said it's the hardest job in the world. I mean I worked full time up till I was 61. And this is, this is the hardest thing [...] I say you've ever got to do is look after somebody. (Joanne)

RELIEF, RECOVERY, REPAIR

- A break can allow carers to experience a release of the pressure built up from caring, which can lead to a substantial change in mood and a sense of relief.
- Carers often highlighted a break as being most beneficial to supporting their mental health.
- Carers understand that breaks are about meeting their needs, whatever they are, and they can use a break in whatever way to meet those needs.
- A break can release them from feelings of burden and responsibility, and to great effect giving them 'Peace of Mind' (Bob).

But when she's gone it's like I'm decompressed. I can relax. [...] it's like a weight lifted off your shoulder and you relax. (Simon)

What it meant for me was the ability to keep on...Um. You know on each occasion I was, um, you know, a hair's breadth away from busted. [...] Without it (a break) I would have been an absolute basket case. (Bryan)

BREAKS GIVE CARERS THEIR LIVES BACK (BRIEFLY)

- A break can help, albeit temporarily, to give a carer a glimpse of their old self, the ability to reconnect with who they are, or the person they could be but for their caring role.
- Carers want a complete break from their caring lives, not just the physical and mental demands of caring, but every aspect, including from the professional services coming into their homes and the visible reminders of caring including medical equipment, such as hoists.
- Breaks give carers the chance to rediscover and focus on their own needs. It can help carers regain important aspects of themselves and their identity that they lose while caring.
- Carers often use breaks to reconnect or stay connected with those social aspects of their lives that are often lost or limited due to caring.

Absolutely, absolutely it (a break) reminds me of who I am. (Joanne)

[...] it's where you have an opportunity to go to a cafe or a restaurant and not have to feed somebody. Yeah, it's a time when you can do that. [...] all the things that you would do if you had the total freedom. (Stuart)

BREAKS DON'T SOLVE EVERYTHING

- The opportunity to have a meaningful break can be easily diminished or lost by unanticipated adverse factors, such as dealing with emergencies, health problems, or even the weather.
- Some carers also experience guilt from leaving their cared-for-person in a respite facility, which impacts on their ability to fully benefit from a break.
- For many any positive effect experienced by a break was often 'fairly short lived' (Lucy)
- Carers want more and longer breaks.

[...] but he's not with you. [...] it is still quite difficult to relax and not feel guilty. (Lucy)

I could probably, well, a longer break to be honest. I could probably have had a longer break. (Sylvia)

4 Discussion and Conclusions

This research demonstrates that breaks facilitated by temporary institutional care are for most carers overwhelmingly positive experiences. They support a carer's wellbeing, enabling them to recover sufficiently from the all-consuming nature of caring to continue to provide care after the break. A break doesn't solve everything though, with carers finding the positive effect of breaks short-lived and wanting longer and more frequent breaks to support them. Furthermore, for breaks to be a positive experience for carers, the right respite centre must be available to support the cared-for-person.

The findings of this research suggest that policymakers exploring how to improve support for carers should consider ensuring that carers get the breaks they need.

References

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