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Navigating the coronavirus pandemic two years on: Experiences of carers of people with dementia from the British IDEAL cohort

Short title: Impact of two years of COVID-19 pandemic on carers of people with dementia

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Abstract

We explored carers experiences during the COVID-19 pandemic in England to identify long-term impacts and implications, and to suggest future support for caregivers.

Data were collected during COVID-19 rapid response studies (IDEAL-CDI; INCLUDE) from carers participating in a British longitudinal cohort study (IDEAL). Semi-structured interview data were compared to their accounts from previous interviews conducted during the first 18 months of the pandemic.

There was indication of some return to pre-pandemic lifestyles but without appropriate support carers risked reaching crisis point. Evidence points to a need for assessment and management of support needs to ensure well-being and sustainable dementia caregiving.

Keywords

COVID, qualitative, care services, quality of life

Word count

7131

Introduction

Carers are individuals who provide care for individuals with a chronic illness or disability that is unpaid or informal. They are crucial for supporting people with dementia living in the community. Caring yields both positive and negative experiences (Lindeza et al, 2020; Quinn et al, 2019; Quinn and Toms, 2018). Several factors influence carers' wellbeing, including their own experiences of caring and their psychological and physical health (Clare et al, 2019). Although carers are often resilient (Dias et al, 2016; Jones et al, 2019; Kalaitzaki et al, 2022) adverse external events or challenges can disrupt the caring equilibrium. The global COVID-19 pandemic (henceforth 'the pandemic') can be viewed as one such event.

Qualitative research from early in the pandemic reported carers experiencing difficult feelings of loneliness, isolation loss of control and uncertainty (Giebel et al, 2021; Hanna et al, 2021; Roach et al, 2021) and poorer health and wellbeing (Sriram et al, 2021). Evidence from surveys also found carers experienced stress (Cohen et al, 2020; Zucca et al, 2021); anxiety, depression, burden (Masterson-Algar et al, 2022; Tsapanou et al, 2021) fatigue (Bacsu et al, 2021) and role overload (Savla et al, 2021). Structured interviews collected from a large British cohort before and during the pandemic showed carers were lonelier, experienced less life satisfaction and felt more captive in their caring role during the pandemic (Quinn et al, 2022). Another longitudinal survey conducted in Portugal found carer burden increased during periods of social restriction when compared to data collected four months prior to the start of the pandemic (Borges-Machado et al, 2020). Other longitudinal surveys have compared responses under differing levels of social restriction in place at different stages during the pandemic (Koh et al, 2020; Lara et al, 2020; Panerai et al, 2020) indicating that increased difficulties in carers' experiences were attributable to the social restrictions imposed. Where changes in carers' wellbeing have been reported, suggested explanations have included disruption to usual support networks (Hanna et al, 2021; Savla et al, 2021) and reduced functional ability or increased behavioural and psychological symptoms of the care recipient (Cohen et al, 2020; Pongan et al, 2021). However, not all longitudinal surveys have found evidence of difficulties. For example, one study found that compared to pre-pandemic levels there was little impact on carers' overall experience of caring and no impact on wellbeing and quality of life (Gamble et al, 2022). In another study there was no change in carers' distress scores during social restrictions compared to eighteen months before the pandemic (Daley et al, 2022), consistent with other similar findings measuring change in quality of life (Carbone et al, 2021; Gamble et al, 2022).

Findings on carers' coping also vary. While some studies reported that carers were coping well (Losada et al, 2022), others have highlighted individual variability in the capacity to cope (O'Rourke et al, 2021; Roach et al, 2021). One explanation may lie in carers' appraisals of their own ability to cope, as suggested by Savla et al (2021) who used the Transactional Theory of Stress and Coping (Lazarus and Folkman, 1984) to examine carers' appraisals of how circumstances early in the pandemic affected their ability to cope. A large questionnaire-based study compared a matched group of carers assessed on two occasions before the pandemic with carers assessed on two occasions during the pandemic and found that, while coping remained stable over time when assessed before the pandemic, during the pandemic carers coped better over time (Gamble et al, 2022). These adaptations are perhaps attributable to an accommodation to circumstances over time and development of coping behaviours (Goodman-Casanova et al, 2020; Savla et al, 2021) or personal resilience (Altieri and Santangelo, 2021). Indeed, Moretti et al (2021) found depression, anxiety and stress scores varied according to the level of pandemic restrictions in place at the time, suggesting that carers adapted to the prevailing circumstances.

The longitudinal evidence highlights the importance of looking at how carers' experiences and coping ability evolved over time to understand the longer-term impact. Much of the existing evidence was collected in the first year of the pandemic. There is a need, therefore, to understand how carers' ability to cope might develop in the longer-term. The overall aim of this qualitative study was to explore carers' experiences approximately two years into the pandemic and, where possible, to compare their accounts with those they gave when interviewed earlier in the pandemic (IDEAL CDI; INCLUDE). We conducted the interviews during a time when social restrictions had eased in England but mask-wearing and working from home were recommended due to the emergence of the Omicron variant, with the aim of identifying longer-term impacts and implications and determining how best to support carers in the future.

Methods

Design

The study reported here was part of the INCLUDE project (Clare et al., 2022; Quinn et al., 2022) set up to explore the experiences of people with dementia and carers during COVID-19 by recruiting people who were participants in the British IDEAL cohort study (Clare et al., 2014; Silarova et al., 2018). Carers were eligible if they were caring for a person with mild-to-moderate dementia living in the community. A small number of IDEAL participants had been interviewed in depth early in the pandemic, in May and July 2020 (O'Rourke et al., 2021) as part of the IDEAL COVID-19 Dementia

Initiative (IDEAL-CDI), and the INCLUDE study built on this approach. INCLUDE participants completed structured telephone or online interviews between September 2020 and April 2021 (Clare et al., 2022; Quinn et al., 2022), and a sub-set was interviewed using qualitative semi-structured interviews at one of two time points nested within the INCLUDE study timeframe: November to December 2020 (Pentecost et al., 2022) or January to April 2021 (Stapley et al., 2022). Table 1 shows how the timeline of INCLUDE data collection relates to the timeframe of the pandemic and associated social restrictions in England. Here, we report findings from a further round of qualitative semi-structured interviews conducted between December 2021 and January 2022 with carers who had been interviewed previously as part of IDEAL-CDI or INCLUDE. The timeframe covered a period of the pandemic when many restrictions were being lifted; the national vaccination programme had been ongoing since its commencement in December 2020, but infection rates were still high, and the new Omicron variant was emerging.

((Table 1. About here))

INCLUDE was approved by Wales Research Ethics Committee 5 as an amendment to IDEAL-2 for England and Wales (18/WS/0111 AM12) and an extension was approved for the current study (18/WA/0111/ AM14). IDEAL was approved by Wales Research Ethics Committee 5 (13/WA/0405) and IDEAL-2 by Wales Research Ethics Committee 5 (18/WS/0111) and Scotland A Research Ethics Committee (18/SS/0037). IDEAL and IDEAL-2 are registered with the UK Clinical Research Network (UKCRN), reference numbers 16593 and 37955. Consent was recorded electronically prior to the interview and a copy of the consent form later sent to the participant either via email or post.

Participants and procedures

Figure 1 illustrates the flow of IDEAL cohort participants through the IDEAL-CDI and INCLUDE qualitative interview studies. We identified 29 carers who had previously taken part in IDEAL-CDI and INCLUDE qualitative semi-structured interviews; 15 met eligibility criteria and were contacted by telephone, and 10 agreed to participate.

Interviews were held remotely by telephone or Zoom according to preference and scheduled at a convenient time for the participant. A trained graduate research assistant (ED) conducted the interviews. The IDEAL advisory group, made up of people with dementia and carers (ALWAYS), contributed to the development of the INCLUDE study including the interview topic guides. These were developed to consider changes to routine and coping strategies, any benefits, and any support or health care suggestions. The topic guide for this set of interviews was based on the previous

INCLUDE qualitative semi-structured interview topic guide and developed with input from our Patient and Public Involvement (ALWAYS) group (Litherland et al. 2018) but adapted to address the COVID-19 situation at the time. Questions were open-ended without a theoretical focus allowing for in-depth exploration of topics important to participants (see Supplementary Table 1). All interviews were audio-recorded and professionally transcribed verbatim.

Data analysis

Data analysis was guided by the seven-stage framework analysis approach (Gale et al, 2013). The transcripts were supplemented by field notes containing observations and reflections made during and immediately after the interview (by RC). Further notes and key ideas from each participant's previous IDEAL-CDI or INCLUDE interview were added, allowing initial comparisons between the previous and current interviews. Familiarization was undertaken by the data analysis team (RC, ED, CP, SS) and involved listening to the new audio recordings, reading the transcripts and annotating the transcripts and field notes. This process enabled the researchers to understand how individuals' experiences at this stage of the pandemic compared with earlier interviews. Weekly discussions amongst the data analysis team supplemented the analysis process and were followed by wider discussions with members of the IDEAL programme team.

An initial coding framework was generated from the coding frameworks used in the previous INCLUDE qualitative studies (by RC) without a theoretical focus. This framework was deductively applied to four randomly selected transcripts which were inductively coded by RC using NVivo 12 (QSR International, 2020). Additional inductively identified codes from the data were added to the deductive framework to highlight new or different experiences or views. RC completed back and forth checking both within and between cases for consistency of coding and re-classified codes as required. RC and ED discussed and agreed the framework and code descriptors. Using the working analytical framework, RC continued to deductively and inductively code and index the remaining interviews whilst checking coding within and between cases. To ensure methodological rigour, SS checked the framework, code names and descriptions of three randomly selected transcripts.

The data analysis team discussed the proposed themes with co-authors and further members of the IDEAL programme team. Details of the development of codes and associated themes and sub-themes from the different time points are presented in Supplementary Table 2. We allowed overlapping of carers' statements to provide a holistic account of varied experiences. The data

analysis team reviewed the themes to identify changes between individual interviews over time or differences in carer experiences.

Results

Sample characteristics

Ten carers participated in interviews between 14 December 2021 and 24 January 2022. The interviews lasted between 28 and 60 minutes. The characteristics of the carers and care recipients are found in Table 2. Five females and five males were interviewed, all but one by telephone (carer 7). The age of the carers ranged from 57-85 years (mean = 71). Most were white and British (70%). Five were university educated. All participants lived in urban or suburban areas. Eight carers were spouses and lived with the person with dementia. The care recipients were 57-94 years old and half were female. Four were diagnosed with Alzheimer's disease and four with frontotemporal dementia, including two with the behavioural variant. One had vascular dementia and in one case the specific dementia diagnosis was unknown. Half of the people had young onset dementia. Time since diagnosis ranged from 3 to 12 years (mean = 6.9).

((Table 2. About here))

Caregiver narratives

Carers provided individual, personal accounts illustrating positive and negative experiences of caregiving and their changing lives during the pandemic. We also identified potential lasting impacts of the pandemic on the carers, their caring role or on the care recipients with dementia. Consistency with or divergence from statements in previous interviews are illustrated for each carer in Supplementary Table 3.

Thematic analysis

Thematic analysis revealed variable experiences of carers of people with dementia approximately two years into the COVID-19 pandemic. The analysis uncovered the fragile balance between carers doing well and not coping. Although changes in local pandemic and personal circumstances meant individual accounts of caring and coping also fluctuated, we identified three themes reflecting key areas of influence on the health and wellbeing of the carers and their ability to cope. These were 'Reassessing 'normal' care' with two subthemes ('cautious optimism' – getting back out there; a new normal but no going back); 'Attitudes and roles of others in supporting carers', with two subthemes

(aiding the caring process; barriers to the caring process); and 'caring under stress'. Illustrative quotes are provided below.

Theme 1: reassessing 'normal' care

This theme identifies views on not being able to return to pre-pandemic life, and the associated implications for their caring. Carers provided mixed accounts, ranging from positive re-evaluation and optimism to dissatisfaction with the changes in their lives. There was also reflection on their own definition of normality, emphasising the fluid nature of caring for somebody with dementia during the COVID-19 pandemic with lack of certainty about current and future routines.

1.1 Cautious optimism – getting back out there

The easing of restrictions allowed some level of return to pre-pandemic 'normality', such as being able to meet up with family and friends and reinvigorating informal support networks. There were some reports of increased opportunities for returning to activities and interests outside the caring role. Some carers stated that dementia services (e.g. memory cafes, day care centres) had started to re-open. This benefitted both partners, providing some time apart and a return to social engagement for the person with dementia:

"She is meeting other people...with the best will in the world, if you are doing things at home all the time just with me, that's quite wearing on both of us...So I think it's a far better balance we have now; to both of our benefits." (carer 7)

The return of dementia services offered carers opportunities to have their own space and respite. However, acknowledging uncertainty about whether services would remain open, carers were taking advantage in case they closed again. Some changes in routine, behaviour or coping strategies that had been established during the pandemic, such as online shopping or the use of online peer support groups, were being maintained as even with the lifting of restrictions these were still beneficial. This was because of the decline in the person with dementia, increased caring responsibilities, or enjoying the convenience.

1.2 A new normal but no going back

This subtheme identifies carers' acknowledgment that the situation now is different from pre-pandemic life. Although some stated they thought life was returning to some level of stability, all carers spoke of an observed decline in functional ability, behaviour or changes in personality in the

person with dementia during the course of the pandemic. Some also indicated that the decline had occurred since they had last been interviewed. This decline in condition was attributed to the natural progression of dementia, the effect of restrictions “because there was no structure, it speeded up his dementia” (carer 9), or a combination of both:

“He’s definitely different. But that’s, I think, more than the pandemic, well, as well as the pandemic. I mean, he’s got dementia, so he’s going to go downhill.” (carer 6)

This decline increased the level of caution regarding whether to return to pre-pandemic activities:

“It’s hard to decide, which is pandemic...or the fact my wife can’t do what she used to do is... is difficult in this... all I can think is, they’re split. But we’re still kind of wary of where we go, so...” (carer 4)

All carers stated they now spent more time caring and had needed to broaden the scope of what their caring role entailed. Several carers now compared their role to being a parent or commented on changes in their relationship with the care recipient. Overall, compared to previous interviews, there was less discussion about keeping the care recipient occupied and more about ensuring the person was content and happy.

Carers provided accounts of activities they had attended prior to the pandemic that were no longer suitable, due to the decline in the person with dementia. They either did not attend external dementia services in person or found an alternative means of support. One carer described how the care recipient, who had been diagnosed with young onset dementia, had previously attended young onset dementia services. However, due to the decline, the need for young onset specialist services was no longer considered necessary by the carer who found that generic dementia services more appropriate for an older clientele were now suitable.

“The group she attended pre-pandemic was geared towards early onset. So they were all people in their late 50s, early 60s. [You know], quite active and... but as the condition progresses, in some ways, she now...It doesn’t matter so much that it’s more of an elderly place; she, you know, she joins in quite happily.” (carer 7)

Three carers also reported that dementia care services that had closed at the beginning of the pandemic had permanently closed, some due to lack of funding. Some carers believed this would further accelerate the deterioration in the person with dementia as the opportunity to engage with others outside the home environment became less available:

“Well, she's not going to get any better, it's going to get worse. And because we don't... they don't... they're not doing the dementia clubs anymore.” (carer 10)

Theme 2: attitudes and roles of others in supporting carers

The behaviour and role of others influenced the carers' ability to care during social restrictions. The attitudes of others also influenced how carers felt about themselves. The attitude and roles of healthcare professionals and family, friends, neighbours or wider society, and the way in which support and information was provided, had positive or negative impacts on carers and their caring experience. Accounts identify how the actions of others changed at different stages of the pandemic and the short- and long-term implications of these.

2.1 Aiding the caring process

Other people's behaviours and actions were shown to influence how carers feel. Most carers relied on paid professionals to provide home care support or domestic tasks. However, where available, there was also a high reliance on local volunteers, friends or family. This dependence on others allowed the carers opportunities to partake in their own interests, undertake other responsibilities, or enjoy personal space. One participant described relying on her daughter so she could return to the choir for 90 minutes a week:

“I mean, all my hobbies have gone except my choir has started off again... I did used to take [person with dementia] before the pandemic, but I don't take him anymore.” (carer 6)

However, other than occasional celebrations, this was only when her daughter was available and thus her only opportunity to have time away from her caring role.

Many carers also provided examples of the existence of fortuitous relationships with people who were able to provide advice, for example relatives who were healthcare professionals, and on whom they relied for information and guidance where official sources were lacking.

Carers also discussed their appreciation of the positive role individuals played, especially those “doing [it] off their own back” (carer 9), and one described her family doctor as “very sympathetic” (carer 2) regarding her caring role which helped her feel supported. One carer described how relationships with family and close friends had changed throughout the pandemic and communication was continuing via remote methods. This impacted on the ability to ask for help, and although the emphasis had shifted to relying on less familiar acquaintances, this would likely continue in the near future.

“I suppose, must get used to the fact that people at a distance are not... are not immediately available. Not in the way they used to be. But instead of which, I find that the community and local friends have come to the fore.” (carer 8)

2.2 Barriers to the caring process

Some attitudes or behaviours of others intentionally or inadvertently had a negative impact on carers. Although there was an overall indication of carers returning to activities outside the home, the presence of COVID-19 was still influencing their decision-making about re-joining groups, using public transport, socialising and keeping the person with dementia safe. Specifically, behaviours of others, such as not respecting personal space, was still causing concern and preventing some carers from fully returning to social interaction outside the home, as they “simply don’t care” or are “just idiots and don't think about other people.” Indeed, even the change in the behaviour of friends at different stages of the pandemic and associated social interaction rules, such as the introduction and removal of ‘support bubbles’, had negative implications. Support bubbles were introduced by the UK Government between June 2020 and July 2021 to assist people living on their own by allowing two eligible households to socialise together:

"At the start of the whole thing one of my friends became in our bubble and so we saw quite a lot of her, but she's... you know it's eased off a bit now and I can't do the things that I used to be able to do." (carer 2)

As with the earlier interviews, there was a feeling that the government and wider society did not consider carers throughout the pandemic, for example by not providing specific guidance or help. This led to a continuation of carers thinking they were being treated “as if we were absolute nobodies” (carer 9) or considered “invisible” (carer 6) and that “nobody seems to care.” (carer 10). This led to continued feelings of abandonment and extended to healthcare professionals:

“The professionals are the ones that sort of like let us down a bit more.” (Carer 9).

Indeed, if support was forthcoming, it was sometimes felt to be “perfunctory” (carer 4), “cursory” (carer 4) or due to someone having “been prompted by somebody else” (carer 9), rather than reflecting a genuine sense of care. When the carers were asked to provide advice about how healthcare professionals or volunteers could best help people in similar situations, most responses were about the need for a more positive attitude and a more proactive approach, for example “be prepared to listen” (carer 1) and “[present a] real feeling that someone's taking an interest” (carer 1). They appreciated the healthcare professionals who showed concern and provided time:

“You just need that open question as to how things are, and have time to have a conversation... Put the pen down, sort of thing and, “How are you?”” (carer 7)

This need for proactive, interested individuals is heightened by the reliance of external dementia services on volunteers. Linking to the subtheme above ‘a new normal but no going back’, one carer highlighted how the lack of volunteers prevented dementia clubs from re-opening:

“They're not doing the dementia clubs anymore, because they can't get the volunteers.” (carer 10).

Theme 3: caring under stress

Carer narratives illustrated how the combination of the pandemic and the deterioration in the person with dementia, along with the extra challenges they were facing, created additional stress and influenced the balance between coping and not coping. Carers were generally open about how they were feeling about their ability to cope, with one carer describing their situation as “totally enveloping” (carer 4) and another saying the pandemic had left her feeling as if her “personal space really doesn't exist now.” (carer 2).

One carer stated that his own perception of how they were coping was different from how others perceived the situation:

“I think I'm coping reasonably, but I'm being reminded by good friends and good daughters that I'm not coping as well as I think I am.” (carer 1)

There was also a belief that carers would benefit from specific carer training as they were “learning on the hoof” (carer 6), especially as the care recipient’s condition deteriorated. This was captured by one carer who highlighted his feelings of doubt around his caring role:

“There's no [training] and it would be so simple to organise. You just think, 'Well I'm doing all these things but actually, am I doing it right? ... for folks like me that would be so useful...if you put a new member of staff into a [residential] care home or something, straight away, you would be put through some kind of training process, wouldn't you?” (carer 7)

This carer then went on to discuss how beneficial it would be to have training on different aspects of dementia care, such as safely moving somebody or strategies for dealing with dementia-related behaviours. Furthermore, there was limited receipt of guidance and support from healthcare professionals and carer services during the pandemic. In one case, support received during the earlier stages of the pandemic had ceased by the time of the interview:

"I: And have you still been receiving phone calls from the [Dementia charity]?

P: No, that's stopped now. That was obviously a temporary thing. But that's now disappeared."
(carer 1)

If they did receive support, it was not always appropriate or available in a useable format: for example, for those without access to the internet. To replace formally organised support groups attended prior to the pandemic some carers had been pro-active and formed informal support groups among themselves. Some groups were initiated and delivered online earlier in the pandemic and were continuing in the same format; others were starting to meet in person with the lifting of social restrictions. However, these groups discussed a limited number of topics and the lack of professional input led to requests or questions unanswered. In addition, talking to healthcare professionals on the telephone rather than face-to-face made one carer feel he had not had the opportunity to fully express himself and was “drawn down a blind alley” (carer 1), left feeling he had not got across what he felt, and had missed an important opportunity.

Carers also divulged some of the challenges and frustrations they had faced when applying for statutory carer support or undergoing financial assessments to reduce caring and financial burdens. Discussions around these topic areas were more prevalent in these interviews than in the interviews earlier in the pandemic. Applications were often delayed, as providers were likely to be dealing with

staff shortages or a backlog of applications as a consequence of the pandemic. With waits of up to 6 months, this lag in support was an added layer of carer stress and burden.

“Social Services, I've struggled with them a little bit. Both making contact and getting what I need.” (carer 6)

For some, the delays or lack of statutory carer or financial support had far-reaching implications, leading to difficult choices. Financial concerns increased due to the impact of the pandemic on the cost of living, particularly for those on fixed incomes or state benefits:

“So you're worried about if you've got enough to pay your heating bill and stuff like that, you know?” (Carer 10)

Carer 10 went on to discuss the impact of the closure of the free local dementia club that had offered musical activities that helped the care recipient, as it “seemed to mellow” her. Financial pressures meant the carer could not afford to replace this by buying their own musical instruments, despite the positive impact.

Since the previous interviews, extra pressures facing carers had arisen, such as a new need to provide care for another family member and the impact of that:

“My mother lives five miles away and is 81. She has now been diagnosed with dementia...So I've got that to consider as well...I've got two people that have got a call on me...my time is pretty pulled hither and thither.” (carer 4)

Furthermore, the impact of the pandemic has caused ongoing delays in referrals to healthcare and initiation of treatment. Many participants who had reported healthcare needs in earlier interviews were now at the point of needing urgent treatment; some, for example, were in constant pain or had mobility issues that affected their ability to care. When asked if he was saying that he felt burnt out with caring, one carer responded:

P: “Yes, absolutely, definitely. I will say though; I'm usually a very patient person, and I think if my health was better, I think I could, sort of, cope with it better. I think that doesn't help because I've got chronic osteoarthritis, and even before the lockdown [restrictions], I was at the top of the emergency list...to have my knees replaced.” (carer 6)

Likewise, one participant felt “much more stressed” (carer 2) than before the pandemic and there was no indication that this level of stress was declining with the lifting of restrictions. This carer expressed the situation well:

“Carers have become very aware that the danger is that the carer can become the patient and the patient can become the carer.” (carer 8)

Discussion

Following from earlier reports (O’Rourke et al, 2021; Pentecost et al, 2022), this qualitative study explored the experiences of carers of people with dementia approximately two years into the COVID-19 pandemic in England during a time when restrictions were being eased. To the best of our knowledge, this is the only qualitative study to compare findings with previous accounts of carers’ experiences earlier in the pandemic. This provides a unique opportunity to study the ongoing impacts and experiences. The findings highlight variability in individual experiences with divergent narratives illustrating diverse personal challenges and circumstances. Regardless of the diversity, we identified common experiences with potentially lasting legacies. This is reflected in three main themes: ‘reassessing ‘normal’ care’; ‘attitudes and roles of others in supporting carers’, and ‘caring under stress’.

We found carers compared their experiences to the past and sought stability and normality where possible. The pandemic brought about sudden, extreme and numerous challenges to deal with, but even with eased restrictions, carers were not back to ‘normal’ in terms of their ability to mix; there were lasting changes to available support and the additional stress of dealing with noticeable decline in the person with dementia. Our data complements quantitative studies showing that a reduction in care recipient functioning or increased behavioural challenges have a detrimental impact on carer resilience (Altieri and Santangelo, 2021; Kalaitzaki et al, 2022; Stapley et al, 2022). Feelings of normality were improved however when restrictions eased, allowing opportunities for some to pursue their normal interests and return to support networks.

The transactional stress model has previously been applied to understand carers’ experience during the pandemic (Salva et al, 2021). The model suggests that in normal circumstances carers may demonstrate resilience and manage stress by appraising changes to their situation as they occur and respond by drawing on internal coping strategies and external resources (Lazarus and Folkman, 1984) in the form of help, support and taking time for themselves. Indeed, carers who benefitted

from both the reopening of formal dementia services (e.g. memory cafés, day support centres) and return of informal support experienced some lowering of burden and increased ability to cope (Savla et al, 2021). However, our findings showed an ongoing and long-lasting impact of external formal care services remaining closed and ongoing uncertainty as to when such services would re-open. The cumulative pressure of such uncertainty, alongside a lack of respite or assistance, increased the likelihood of harmful levels of stress, suggesting stress was not simply a challenge that could be overcome through positive reappraisal or a different response (Lazarus and Folkman, 1984). In addition, carers experienced isolation due to continued caution around COVID-19 and/or the new normal of increased caring needs of the care recipient. Our evidence supports earlier findings predicting that the combination of advancing dementia with the evolving pandemic was likely to exacerbate carer stress, burden and feelings of isolation and abandonment (Bacsu et al, 2021; Boutoleau-Bretonnière et al, 2020; Cohen et al, 2020; Hanna et al, 2021; Zucca et al, 2021).

The carer experience was influenced by precarious dependence on the actions of others. Despite the fact that dementia carers often need more respite services than carers of people without dementia (Lee et al, 2022), our findings showed carers responded to the absence of formal respite by taking advantage of informal sources of support and information where possible. Although this was highly valued, there was a risk that stress could return when gains in networks and relationships during the pandemic were not available longer-term due to the return to pre-pandemic life for those people in newly developed support networks. A sense of abandonment and feeling of being left to cope alone had not improved from earlier stages of the pandemic (Giebel et al, 2021; Hanna et al, 2021; Pentecost et al, 2022; Zucca et al, 2021). Carers not receiving enough support appropriate to their need and situation, especially those caring for somebody with more advanced dementia, are likely to experience role overload, reduced health (Gaugler et al, 2003; Savla et al, 2021) or 'burnout' (Lilly et al, 2012). Indeed, a study conducted in New Zealand and Hong Kong identified personal characteristics similar to those of our cohort (being a spouse or partner, delivering more than 21 hours of care per week, and supporting those with basic daily care needs) as risk factors for burnout (Chan et al, 2021).

Even as restrictions had eased, in addition to increased caring demands, some carers also contended with challenges in meeting their own health, practical or financial needs caused by the delays, changes to, or closure of various usual services. Unfortunately, a shift from coping to not coping was evident in carers expressing doubt in their ability to care. Our data has indicated that stress accumulated and became unmanageable more quickly than may have been the case pre-pandemic.

Unfortunately, although at the time of our study restrictions had eased significantly, experiences of stress were similar to experiences of carers earlier in the pandemic, such as a decline in carer quality of life and wellbeing (Clare et al, 2022; Kürten et al, 2021), increased burden (Lethin et al, 2020; Lindt et al, 2020) and depression (Schoenmakers et al, 2010). We therefore echo the value of standardized needs assessments for carers to ensure effective support is provided quickly and efficiently and the risk of burnout is reduced (Chan et al, 2021).

Having access to certain health services provides some protection from carer burnout (Chan et al, 2021), and our study further supports the positive role dementia services bring to both the care recipient and carer (Hanna et al, 2021). However, our work indicated that the already fragmented receipt of post-diagnostic support for people with dementia and carers in England (van Horik et al., 2022) has likely become even more disparate during the pandemic, continuing to deteriorate after pandemic restrictions eased. Carers had few options in receiving externally delivered formal care services or home-delivered statutory care services. Although we did not set out to compare pre-pandemic and current experiences of formal services, carers' accounts indicated they were finding the experience of using formal services very different. As seen in our earlier interviews (O'Rourke et al., 2021; Pentecost et al., 2022), the offers of nurse visits or regular 'checking in' telephone calls that had started early in the pandemic from charities and volunteers became limited, or stopped. Therefore, opportunities to assess carers' wellbeing were missed. Although volunteers are a valuable, cost-effective resource to help provide care for people with dementia (Malmedal et al, 2020; Norwegian Ministry of Health and Care Services, 2015), the checking in services were a temporary measure at the start of the pandemic and were not sustainably funded. Our previous research recommended that with the absence of in-person health services, telephone contact would have been helpful (O'Rourke et al, 2021). The use of telephone consultations could be a valid alternative method of delivering proactive support for carers unable to see healthcare professionals in person (Waller et al, 2017) but evidence suggests more work is needed to ensure these are appropriate and well executed (Pentecost et al, 2022). Although telephone or online services can be beneficial they may not mitigate carer burnout for all, and it is important not to simply replace face-to-face services with telemedicine, as this can exacerbate inequalities in service provision (Tuijt et al, 2021). To improve support for carers of people with dementia, policymakers and service providers should recognise the longer term impact of the reduction in services and the need for appropriate funding

Limitations and strengths

This study has some limitations. Firstly, convenience sampling was employed using a relatively small pool of participants who had taken part in previous interviews reported in one of two studies (IDEAL-CDI or INCLUDE), limiting diversity in the sample. For example, the participants lived in suburban or urban settings and findings may not transfer straightforwardly to those living in rural areas. The pool was further restricted through attrition due to factors such as illness, not wanting to participate in further interviews or because the care recipient had moved into full time residential care, and this affected the availability of qualitative data at all previous timepoints for all participants. Secondly the extent of variability between and within individual experiences creates challenges for gaining a clear picture of change over time. We have attempted to identify some generalities and draw out implications that reflect the nature of the changing situation. Our previous quantitative data showed that, overall, carers believed they had coped very or fairly well during the pandemic (Quinn et al., 2022) and wellbeing and quality of life did not decline (Daley et al, 2022; Gamble et al, 2022). One reason may be that the quantitative measures used did not have sufficient discriminative capacity, or did not ask the right questions to identify subtle changes (Schoenmakers et al., 2010), thereby confirming the importance of also conducting qualitative interviews, especially over multiple time points, to tease out nuances in experience and provide a more contextualised picture. This is particularly relevant due to the evolving nature of the pandemic, with the recurring cycle of tightening and release from restrictions and local variation in restrictions due to infection rates.

These limitations are counterbalanced by the uniqueness of having a qualitative longitudinal aspect to explore carer experiences at different timeframes of the pandemic. We believe, to the best of our knowledge, this to be the only qualitative study that includes comparisons of carer experiences at different stages of the pandemic. Furthermore, we were able to compare and contrast findings from more in-depth interviews with quantitative data using the same cohort of participants. This created a valuable opportunity to understand the subtle experiences of carers of people with dementia.

Conclusions

This study has provided evidence about carer experiences approximately two years into the COVID-19 pandemic that could be compared with earlier qualitative interviews. As the UK population was being urged to 'live with COVID-19', this study highlights the position of carers, for whom the normal equilibrium of challenges and resources was unbalanced more quickly than would have been the case pre-pandemic. The lifting of restrictions and availability of a national vaccination programme approximately two years into the pandemic allowed for some return to pre-pandemic lifestyles but carers were still assessing ways to cope. Risks to coping primarily concerned the increased demands

created by lack of support with the cognitive decline of the care recipient alongside reduced interaction with others due to ongoing COVID-19 fears, and changes to availability of formal care services and informal support networks. In addition, delays in the provision of practical, emotional, health or financial support for themselves compounded their ability to cope. Carer needs created by the pandemic were new, more extensive and ongoing, and there is thus a realistic danger of dementia carers reaching crisis point and burnout. To protect carers, and for caring in the community to be sustainable, carers would benefit from access to care advice, and to dementia groups and services and support suitable for different stages of the dementia journey. Carers would benefit from regular assessment of their individual support needs. This is not only essential for recovery post- pandemic but to protect the sustainability of carer support in the future.

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Data access statement:

IDEAL data were deposited with the UK data archive in April 2020. Details of how the data can be accessed after that date can be found here: <https://reshare.ukdataservice.ac.uk/854293>

INCLUDE data were deposited with the UK data archive in June 2022 and will be available to access from July 2023. Details of how the data can be accessed after that date can be found here: <https://reshare.ukdataservice.ac.uk/855800/>

Conflict of interest:

The Authors declare that there is no conflict of interest

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Figure 1. Flowchart showing participation in the longitudinal interview study interviews

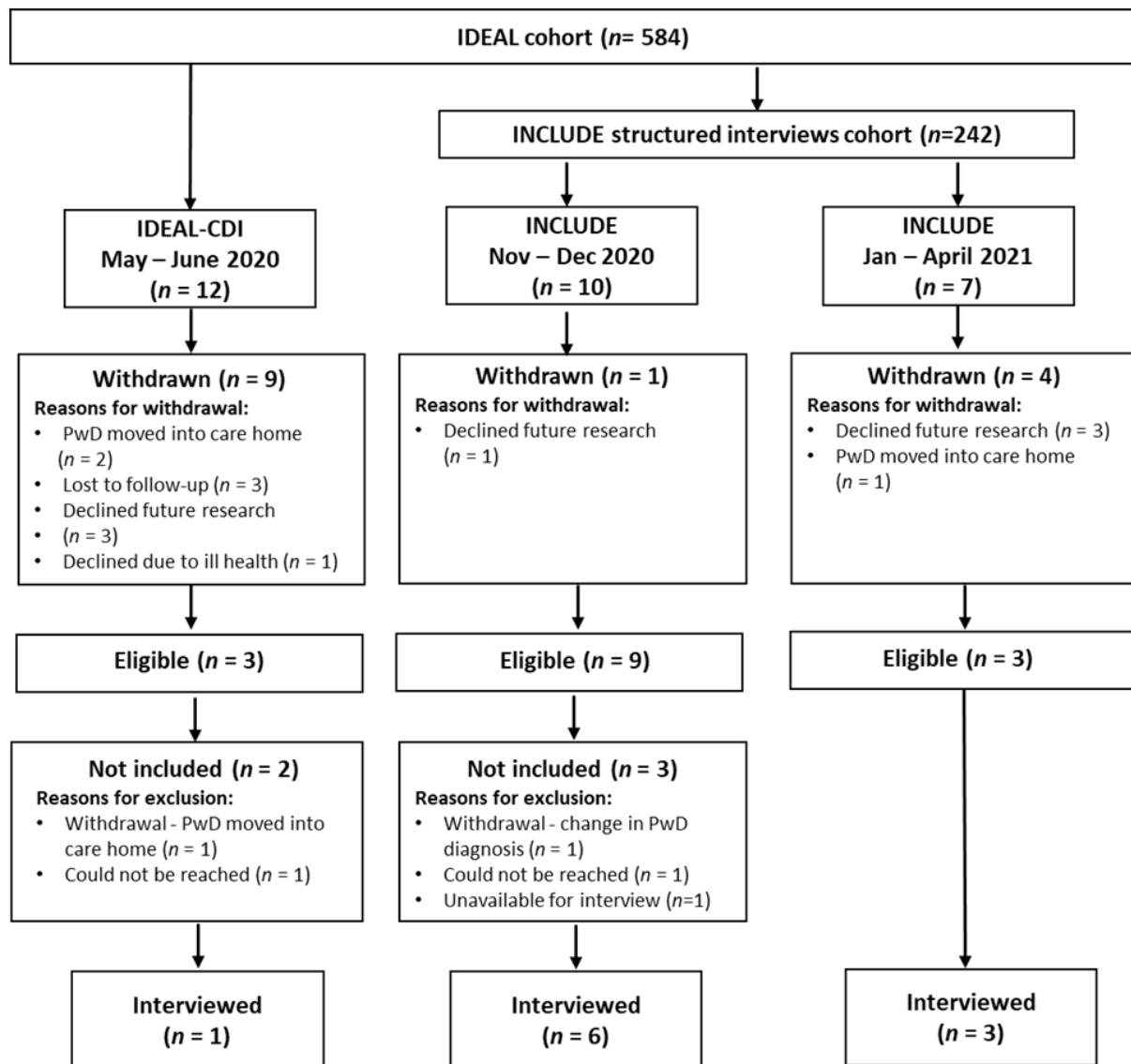


Table 1. Timeframe of INCLUDE data collection in relation to UK Government measures to manage the COVID pandemic

Date	Mar 20	Apr 20	May 20	Jun 20	Jul 20	Aug 20	Sep 20	Oct 20	Nov 20	Dec 20	Jan 20	Feb 21	Mar 21	Apr 21	May 21	Jun 21	Jul 21	Aug 21	Sep 21	Oct 21	Nov 21	Dec 21	Jan 22
Government measures	Major national social restrictions				Local restrictions		Major national and local social restrictions						Easing of social restrictions										
											National vaccination programme										Omicron variant; Booster vaccinations		
Data collection			IDEAL-CDI Study ¹	*																			
								INCLUDE Quantitative data collection															
										INCLUDE interviews ²													
												INCLUDE interviews ³											
																						INCLUDE current study ⁴	

Note: Qualitative Semi-structured interviews with: ¹11 carers plus *follow up (2 carers); ²13 carers; ³7 carers; ⁴10 carers

Table 2.*Characteristics of the carers and care recipients*

Participant/Interview duration(min)	Carer								Person with dementia				
	Previous interview	Age	Sex	Ethnicity	Education	Location	Relationship	Living situation	Diagnosis type	Sex	Age	YOD ¹	Years since diagnosis
1(34)	INCLUDE*	75	M	White British	University/professional qualification	Suburban	Spouse	Together	AD	F	77	-	8
2(43)	INCLUDE*	79	F	White British	Vocational qualification	Urban - Town	Spouse	Together	FTD	M	69	-	8
3(46)	INCLUDE*	71	M	White British	Vocational qualification	Urban - City	Partner	Separate	AD	F	67	Yes	3
4(28)	INCLUDE [†]	61	M	White Other	University/professional qualification	Suburban	Spouse	Together	FTD ²	F	59	Yes	4
5(37)	INCLUDE*	73	F	White British	University/professional qualification	Urban Town	Spouse	Together	FTD ²	M	72	Yes	12
6(52)	IDEAL-CDI	74	F	White British	School leaving certificate at age 16	Urban - Town	Spouse	Together	VaD	M	77	-	10
7(49)	INCLUDE*	62	M	White British	University/professional qualification	Urban - Town	Spouse	Together	AD	F	62	Yes	5
8(60)	INCLUDE [†]	85	F	White Other	University/professional qualification	Urban - Town	Partner	Separate	AD	M	94	-	6
9(47)	INCLUDE*	73	F	White British	Vocational qualification	Urban - City	Spouse	Together	FTD	M	76	-	6
10(37)	INCLUDE [†]	57	M	White NZ	School leaving certificate at age 16	Urban - Town	Spouse	Together	Other ³	F	57	Yes	7

Note:

IDEAL-CDI (May-July 2020) (O'Rourke et al., 2021); INCLUDE* (November-December 2020) (Pentecost et al., 2022); INCLUDE[†] (January – April 2021) (Stapley et al., 2022)

Alzheimer's disease, AD; vascular dementia, VaD; frontotemporal dementia, FTD

¹YOD –Young onset dementia refers to a diagnosis made before the age of 65 (Rossor et al., 2010); ²Behavioural variant; ³Dementia caused by severe epilepsy & neurosurgery

Supplementary Table 1

Topic guide for semi-structured interviews with carers of people with dementia

Topic	Main Questions	Prompts/Probes (not exhaustive)
Difficulties or changes to daily routines	Is life getting 'back to normal' for you yet?	<p>Going out; seeing family/friends; shopping; PwD attending dementia groups AND/OR specific prompt</p> <p>Specific prompts: (Return to normal/reconnecting with world, concerns? Impact of Omicron variant and restrictions, shielding, protecting PwD – COVID risk, Specific prompts: (PwD decline (how?), lost self-confidence? Increased care needs?</p>
	Are you able to do everything you want to do at the moment	<p>How? Why not? What would help?</p> <p>AND/OR specific prompts (e.g. Own interests/hobbies/activities prompt, Garden (weather), creative (knitting, woodwork) TV/radio, clubs, cooking</p>
Own coping strategies and/or support found to be helpful	How do you feel you are coping now, at this stage of the pandemic?	<p>Specific prompts (e.g. burnout caring for PwD /caring in isolation, collective experience?)</p> <p>If coping: what helps you cope? e.g. strong/resilient, keeping busy, learning new skills, talking to friends/family, exercise, pets</p> <p>If not coping: why? What would help you to cope? E.g. Help from family, friends, neighbours, local community, GP, memory service, charity, paid carers, social care, day care, respite, financial support?</p> <p>If last interview was negative, how do you feel you are coping now compared to...?</p> <p>Specific prompts (e.g. not having to go out; more time)</p>
	What's the easiest thing to cope with at the moment?	<p>Specific prompts (e.g. not seeing family/friends; loss of dementia/carer groups; staying indoors; living situation; health)</p>
	What's the hardest thing to cope with at the moment?	
Additional or missing support or information that would be helpful	What information or support do you need now that you aren't getting?	<p>Practical help; emotional support; checking in; advice from a dementia specialist/carers group; financial help</p> <p>Specific prompts (e.g. forgotten/abandoned, didn't get help e.g. wellbeing calls)</p>

		Specific prompts (e.g. How support <u>now</u> compares to pre-pandemic, appropriate, missing?)
	How is your access to healthcare services, such as GP appointments, now?	Specific prompts (e.g. appointments, Face-to-face, alternatives (phone/video call), suitability, get what you need, continuation of care)
Any unexpected benefits or outcomes; and how they might be maintained	Has there been anything positive to come out of the pandemic?	Support from/getting to know neighbours; doing more activities with PwD; more relaxed. If yes, why?
Training or information health or social care professionals or volunteers need to help people with memory difficulties in the COVID-19 situation	If you could give a healthcare professional (e.g. a GP) or someone like a volunteer one piece of advice to best help people with memory problems at this point of the pandemic, what would it be?	Specific prompts (e.g. 'pro-active' service support; practical support; training)

Supplementary Table 2

Summary of the coding framework and development of themes and subthemes

Theme	Subtheme	Origin of framework	Code	Time-point specific sub- code
1. Reassessing 'normal' care		New	A new normal	How life is at interview time point
		CDI/INCLUDE	Attitudes towards the pandemic	
	1.1 Cautious optimism - Getting back out there	New	Going out more or returning to some level of normality	
		CDI/INCLUDE	Receiving some support	Receiving a new source or returned support
		CDI/INCLUDE	Attitudes towards the pandemic	
		CDI/INCLUDE	To risk of getting COVID-19	
		CDI/INCLUDE	To the future (including vaccines and new variants)	
		New	Maintained (beneficial) change in behaviour or routine regarding pandemic	
		CDI/INCLUDE	Benefits of pandemic	
		CDI/INCLUDE	Decline in PwD	Decline between interviews
		1.2 A new normal but no going back	New	Support or care seeking behaviour by PwD
	New		Comparison to being a parent	
	New		Increased amount or variety care provision	
	New		Unable to plan or consider going out	
	New		PwD contented or happy	
	CDI/INCLUDE		Lack of external dementia service support:	Services have not resumed
				Services have permanently closed Activity or support no longer suitable for PwD
	CDI/INCLUDE		Challenges as a result of pandemic	
	New		Negative emotional response to caring for PwD	

2. Attitudes and roles of others in supporting cares	2.1 Aiding the caring process	New	Dependent on others	
		CDI/INCLUDE	Benefits of pandemic	
		CDI/INCLUDE	Experience of health providers or care received (Positive)	
		CDI/INCLUDE	Attitudes towards the pandemic: To risk of getting Covid (influence of others and social attitudes - positive)	
	2.2 Barriers to the caring process	CDI/INCLUDE	Need for dementia awareness in wider community or society	
		CDI/INCLUDE	Attitudes towards the pandemic: To risk of getting Covid (influence of others and social attitudes - negative)	
		CDI/INCLUDE	Caring in isolation - limited or lack of informal support -	Informal support stopped or reduced
		CDI/INCLUDE	Experience of health providers or care received (Negative)	
3. Caring under stress		New	Loss of own life or personality	
		New	Support to carers doesn't meet need	
		CDI/INCLUDE	Support required e.g. caregiving assessments, financial	
		New	Pro-active seeking of support or information	
		CDI/INCLUDE	Conflicting pressures	New pressures since previous interview
		CDI/INCLUDE	Own healthcare needs	
		CDI/INCLUDE	Lack of personal time	

Supplementary Table 3

Comparison of carers' experiences at different stages of the pandemic

Carer	Key Experiences from INCLUDE Interview	Key Experiences from Current INCLUDE Interview (Dec 2021-Jan 2022)
	IDEAL-CDI (May-July 2020)	
6	<ul style="list-style-type: none"> • Struggling to provide level of care required to meet PwD needs • Difficulties in relationship, emotionally struggling • Loss of paid carers, respite opportunities e.g. through loss of memory club • Loss of social activities • Easing of restrictions – being reunited with families was welcomed • 'Just checking' services – highly valued 	<ul style="list-style-type: none"> • PwD more dependent • Sleep disruption impacting on health • Struggling to cope, compounded by own health issues not being met • Cautious to protect them both • PwD attending day centre, return to own interest group (choir) • Social 'Bubble' with daughter who offers some respite • Continuation of monthly 'checking in' services from carers' group key worker • Can call admiral nurses if needed. • Key worker checks in monthly but increases frequency if SP is struggling • Think carers are always forgotten
	INCLUDE (Nov-Dec 2020)	
1	<ul style="list-style-type: none"> • Abrupt changes to routine • No external support (All services ceased) • Challenges with internet food shopping • Difficulties keeping PwD occupied • Importance of going out on walks • Need to plan when/where to go • Some welfare calls from dementia charity. • Need joined up, pro-active support, central source of information • Not received any contact from local government • Pandemic information confusing 	<ul style="list-style-type: none"> • Others observe carer not coping as well • 'very little time for non-essentials' • PwD significant decline • Still avoids unnecessary mixing and not going out • Meets up with friends and paid carer offers some respite • Continued with online food shopping – safer and easier • Welfare calls from dementia charity stopped, only call them in crisis • Joined a new Zoom carers group • Need day centre support for PwD • Neighbours and friends more sensitive, increased sense of community
2	<ul style="list-style-type: none"> • Initial problems with food shopping but became confident to do online shopping • Learnt how to cook • Routine altered so used distraction techniques to help cope. • Support from family 	<ul style="list-style-type: none"> • Continued getting food deliveries - getting older and it's helpful • Increased levels of stress • Decline in PwD • Missing interaction with others, meets friends occasionally • Worsening own health needs

- Importance of the garden and walking
- Found it more challenging as pandemic progressed
- Needed Better delivery of information

- 3
- Initial problems with food shopping
 - Increased anxiety around basic needs for PwD
 - Importance of long walks, picnics, garden and nature
 - Keeping in touch with friends via the phone
 - Living in the moment and taking each day at a time
 - Support from dementia carers group
 - Society more friendly
 - Healthcare services became more accessible as pandemic progressed

- 5
- Everything is different – no social activities
 - Deterioration in PwD and more dependent on others
 - More isolated and lonely
 - Friends and family help with shopping, walking dog and domestic work
 - In contact with family using a 'portal' for Zoom
 - Able to continue pottery on Saturdays
 - Rely on family who work in NHS for information
 - Important to keep routine with PwD

- 7
- PwD groups stopped so respite lost
 - Family contact is remote
 - PwD had COVID at start of pandemic - difficulty of trying to communicate PwD symptoms to healthcare professionals

- Carer and PwD attend different groups offering some respite
- Importance of gardens and walks
- Help from cleaner and gardener
- Need financial support

- Returning to pre-pandemic life
- Dementia progression – 'natural progression' but marked
- PwD looked after by paid carers 4 days a week
- Attends various groups including mindfulness but not carer group
- Avoids local news as it can be a source of anxiety
- More funding needed for health and social care
- Believe healthcare services have improved

- Routine has completely changed but for the better. Less pressure now previously their routine was structured around dementia groups. More freedom now to spend time together and do what they want
- Previous activities no longer appropriate for PwD's stage: 'you have to change as dementia changes'
- Dementia progression – lacks motivation
- Own health deteriorated - eye sight and balance
- Lost confidence Company and support of friend very important
- More time for doing things e.g. garden centre, planned holidays
- Daughter a doctor so gives advice
- Visits Psychiatrist every 6 months who is good at explaining conditions
- Finds telephone health appointments not always appropriate
- Neighbours keep their eye on you more and ask how you are
- Realise priorities; 'closer as a family'

- Life ebbing away hard to cope with
- Careful but happy to mix with others. Fully vaccinated so confident to go out
- PwD decline, increased basic care needs

- Creating a routine around physical activity, walking and PwD interests
- Zoom meetings with family and friends
- Formed support bubble with PwD's mum
- Felt more 'reaching out' by groups and dementia charity would have been helpful
- Felt 'left to it'
- Not likely to ask for help but if asked, more likely to disclose his needs
- Returning to carer groups would be of benefit

- 9
- Big change to routine and quality of life
 - Exerted extreme caution by not going out, seeing family in limited way (concerns about passing on the virus to PwD)
 - PwD's activities are very limited, big deterioration in confusion, engagement, abilities
 - Practical help from family (shopping, maintenance)
 - Nurse now coming to see carer for arthritis and checks PwD
 - Keeps busy doing tasks at home e.g. garden, knitting, walking dog
 - PwD tries to read, do pottery & jigsaw but thinks he can't
 - Art group sent things to do
 - Nothing seems to help and carer seems resigned to this
 - Enjoys talking to people but has no respite now
 - Did have calls from dementia charity but that stopped
 - Doesn't use computer
 - Feels 'targeted' as an older person

- Aspects of routine have remained (e.g. Pilates) plus more stimulating activities
- Resumed dementia support groups (changed from YOD focus pre-pandemic to groups with more elderly people)
- Respite resumed – able to go back to golf, good for fitness. Better balance for both
- Zoom groups with family and friends continued
- PwD benefitted from daily routine initially but now enjoys variety
- Lack of proactive contact from external agents

- Coping most of the time but made harder by own health concerns
- Memory café not yet open and unlikely to return
- Dementia progression – loss of structure and routine initially has led to marked decline
- More freedom and mixing more but very conscious and avoids public transport
- PwD goes to art therapy group and day centre, which offers respite
- Good informal support network, closer relationships with family
- Had access to healthcare including face-to-face appointments
- Dementia charity 'could have done more' e.g. wellbeing calls would have helped, and more communication

INCLUDE (Jan-Apr 2021)

- | | |
|--|---|
| <p>4</p> <ul style="list-style-type: none">• Challenge of trying to keep PwD's mind active• Lack of social contact especially with family• PwD unable to speak due to FTD so lack of conversation• Challenging as pandemic progressed as no social contact• Exercise helps – gets a 'buzz'• Nurse visits every 6 months but lack of support from time of diagnosis – 'nothing from them is pro-active'• Social services are dismissive• Day centre not suitable as focussed on older clients• Difficulty in accessing incontinence nurse• Rely on relatives who work in healthcare services | <ul style="list-style-type: none">• Continue to protect PwD from COVID throughout pandemic• Decline in PwD with increased caring responsibilities - very few respite opportunities• No communication with people other than through social media and the telephone• Own philosophy 'don't give up, don't give in, don't run away'• Exercise helps – walking and going shopping• Having to seek own support but now has access to care coordinator• Social services – huge delays, remain dismissive• Nurse used to come every 6 months pre-pandemic to assess PwD (dementia review) but stopped• Declined in local charity support since previous staff member left• Good support from pharmacy |
| <p>8</p> <ul style="list-style-type: none">• Concerns over managing care especially given own age• No social contact at home for 4 months and misses own family• Living on 'high level of adrenaline' as waits for 'next difficulty'• Little time for herself and doesn't trust herself to keep going forever without a break• Created good routine in place for care• Deep connection remains as PwD personality not changed• 3 hours per week respite and part of a writing group• Uses Zoom to keep in contact with family• Social services input 'anticipatory' and 'not when crisis arises'; Feels once you pay for your own help and left on own• Good community (e.g. offered to get shopping) | <ul style="list-style-type: none">• Life has become more difficult• Noticeable decline in PwD and is 'mentally he's withdrawing'• Relationship with PwD changed – his decline has affected their cognitive relationship and communication and has increased care needs• Relationships with own family changing – having to try and maintain contact remotely but PwD family have become more supportive• Own memory concerns have emerged in last year• Receiving support from interest groups• Good routine in place now so less sleep deprived• Carers come in several times a week• Feels fortunate to be 'rich in support' – GPs, community, pharmacy, community, friends• Receives monthly care allowance |

- 10**
- 'Been hell', caring 24/7 without respite
 - Shielded PwD during pandemic so feeling exhausted
 - No internet/mobile devices in the house
 - Feels alone and that 'no one really cares', 'nobody cares about the carer'
 - Dementia support group stopped – not sure if/when restarting. No information
 - Respite care unavailable
 - PwD declined, gets frustrated and shouts
 - Paid carer comes in to get wife up/dressed plus 3 hours a week
 - Gardening/ walking dog/ sleep only means of respite
 - Tried art therapy at home (e.g. colouring in) but short-lived
 - Fighting for care with Local Authority
 - Seeks out own information and passes it on to others
 - More funding to dementia charity needed
 - Dementia progression and increased caring responsibilities
 - Dementia club not restarting due to lack of volunteers
 - Can't afford art therapy clubs or dementia groups
 - No computer so can't join online groups
 - Paid carers come in in the mornings and for 3 hours a week
 - Only respite is sleep
 - Routines are key
 - Tries art therapy but PwD 'has to be in the mood'
 - Feels abandoned. 'No-one cares about the carer'
 - Hasn't heard from link worker in a while
 - Unable to access dementia support because he can't afford the privately run clubs and the voluntary clubs have shut down
 - No time to think about his own health
 - Need more support from doctors and free dementia clubs again