Supplementary Material 1

**Positionality Statement and Reflective Commentary**

Being aware of the active role I have on this research process, I want to begin by writing a personal reflection on my relation with the topic and my positionality. This exercise aims to enhance awareness into my own beliefs, preconceptions and processes in strive for transparency.

I have gained experience working with persons with dementia and other neurodegenerative conditions throughout my career, still in its relatively early phase, while training in Clinical Neuropsychology, completing my PhD focusing on persons with a diagnosis of Motor Neuron Disease, and undertaking a placement in a mental health service for the older adult as part of my Clinical Psychology training. Working with older persons, and particularly those afflicted with dementia, is an area of great interest to me. I feel very passionate about the neuropsychology of dementia and the clinical evaluation and differential diagnostic process, and this is how my interest in the area of dementia started. Over the years, however, in my professional interactions with persons with dementia and their families I have become more and more aware of how much broader their psychological needs are and how this is an area I would like to dedicate myself to in the coming years in my professional career. I consider the experience gained during my PhD the most valuable in gaining such awareness. I travelled around Ireland visiting persons diagnosed with Motor Neuron Disease and had the opportunity to share honest conversations with them and their families, conversations I still carry with me. I think this is why I really want to complete this project, because I am conscious of the challenge that persons with dementia and their families face on a daily basis when dealing with such a devastating condition, and I have also experienced first person the difficulties that the COVID-19 pandemic has posed in all. Thus, I really want to have the opportunity to listen to persons who, on top of having to perform the challenging role that caregiving is, had to do so in such unprecedented circumstances.

I recognise that I have preconceptions of what I believe caregivers most likely experienced based on my personal experience and being informed by what I read in existing research evidence, and I understand the importance of being mindful of this throughout the research process. I anticipate that the caregiving experience in times of COVID-19 was significantly challenging when I think of the uncertainty the pandemic brought. It all began rather suddenly, not giving caregivers a chance to plan, and it was unknown at the time of the outbreak for how long it was going to last or how bad it was going to get. Trying to protect a vulnerable family member from a disease that was hugely feared at the time and would most likely complicate their already delicate health must have been very stressful, considering that a lot of persons with dementia would struggle to understand the risks associated with a COVID-19 infection. Caregivers had limited access to formal supports and had to make difficult decisions around balancing the access to supports and keeping their loved one safe. I am also mindful of caregivers who didn’t live in the same household as the care-recipient and the stress this could have added. I also wonder if caregivers were aware of the impact that disrupted routines and the lack of predictability and stability was having on their loved one with dementia, and if they were concerned about it at the time. Or whether they were worried about how the lockdown and lack of stimulation was further affecting their loved one’s cognitive, psychological, emotional and functional ability. I anticipate that most caregivers found telemedicine insufficient to meet their needs, particularly at a time of such uncertainty and concern. And one must not forget that, like the rest of us, caregivers were also experiencing their own personal difficulties and challenges in relation to the pandemic.

I am aware that my preconceptions are very much focused on the difficulties, and I hope that this research may offer the chance to hear about any opportunities caregivers encountered. I approach this project with an open mind but remaining aware of my preconceptions and the importance of engaging in reflective and reflexive thinking throughout the research process. And I appreciate the role that my academic and site supervisors will have on supporting me with this.

*MPG*

*20th of June 2022*

Supplementary Material 2

Dementia Caregiving during the COVID-19 Pandemic:

An Interpretative Phenomenological Analysis of Informal Caregivers’ Experiences.

Interview schedule

1. Can you tell me a bit about your role as a caregiver for a loved on with dementia? (*descriptive*)

*Possible prompts:*

* How are you related to the person with dementia?
* Tell me a bit about their diagnosis.
* What does being the primary caregiver involve for you?

1. Can you tell me about your experience caring for a loved one with dementia during the COVID-19 pandemic? (*narrative/analytical*)

*Possible prompts:*

* How would you describe it?
* What was different about it?
* How did you feel about it?
* What did you find difficult about it?
* What did you find easy about it?
* Can you tell me how it was like when things started to reopen?
* How does it feel, reflecting on it now?
* What helped?

1. Before we finish up, I am going to ask you to take a moment to think back at everything you have told me. Is there anything else you would like to add?

Supplementary Material 3

| Qualitative Extracts from Interview Transcriptions. | |
| --- | --- |
| **The ambivalent experience of caregiving** | |
| *Those complex emotional experiences* | |
| [1] | *“Well, first of all, I live miles away from her and I don't drive. So [names husband] had to drive me down all the time. I might get two or three calls a day to go down. […] And we always had the worry that she might fall…” (Susan)* |
| [2] | *“Being the primary care is enclosure, if you like. I've been enclosed here, imprisoned, if you like, because it's 24 hours care and it has been horrific in the past.” (John)*  *“I adore my wife, absolutely adore her. And I think I genuinely adore her even more now because she's so vulnerable. But she just looks at you at the same time now and again, where you can see love in her eyes. It's incredible.” (John)* |
| [3] | *“I felt, I don't want to lose Mum because, I mean, she was there every day... […] And she was so independent. She drove her own car up until a few years ago, and she was just amazing. […] And that's why I think we couldn't accept that, that Mum was having this problem and we couldn't help her. We were helpless… […] The loneliness would take over, and, you know… I suppose now I can deal with it a bit better… but I can’t never accept it. ‘How could Mum get this?’ […] I mean, if she was a frail little lady and had major health problems through her life… but she didn't! […] And she'll always say to me, ‘how do I look today?’, and she looks remarkably well, she really does. Like, you wouldn't put her down for her age. And her determination… it was always in her, yeah, always. Even the way she bounced back from the two hip operations…” (Susan)* |
| **Navigating lockdown: lived challenges and opportunities** | |
| *The pervasive fear* | |
| [4] | “*Even her children were afraid to come down […] in case they might have COVID. And even neighbours wouldn't come near you.”* *(John)* |
| [5] | “*Like, Dad's in his 60s, he has diabetes and you look at all the research on it and the fear of any comorbidity with it... It's so worrying…”* *(Carol)* |
| [6] | “*As a carer, I was petrified she'd get it. I didn't want her leaving the world the way it was.”* *(Mary)* |
| [7] | *“The contact with her neighbour, I think, was one of the biggest things that impacted her, that, you know, she didn't have that regular contact and then the lines began to blur about who that person was over time.” (Ann)*  *“So I suppose COVID, that’s one thing, if she had been interactive […] it might have given her something to look forward to rather than fear.” (Mary)* |
| [8] | *“And then, my big worry was… because I am vulnerable if I get sick… if anything happens to me, who is going to mind her? There was no one to mind her… no. She has other kids, she has others, but they don't bother.” (Mary)* |
| [9] | *“My sister and I are very close, so we would’ve talked a lot during that period. So, you know, having the support of somebody who understands is huge, makes a big difference.” (Ann)* |
| [10] | *“COVID has changed everything. I think it's changed us as people... We’re more fearful of everything. Like, look at this strep A virus… the minute they start reporting about it it’s like ‘oh, God, is this another pandemic waiting to happen?’. Then you think, ‘Is it the media on high doh because we've been up to high doh for the last few years?’… I think the world we live in is different.” (Carol)* |
| [11] | *“It didn't fear us too much. We still kept going down. We had to. We had to. And as I said, we just took every precaution and hoped for the best. But Mum was the priority. It really wasn't COVID at that stage. Mum had been through enough a lot at that stage, and we just took the necessary precautions and dealt with it.” (Susan)* |
| *Intensification of existing struggles* | |
| [12] | *“It was extremely hard because he couldn’t understand what the lockdown was. […] He did not understand why nobody was calling to see him or why we couldn't take him out anywhere or where everybody went… […] And it was constant during the day… ‘Where are we going now?’, ‘There's a lockdown…’, and you might have said it a thousand times a day, and he still didn't understand… […] It's very hard and frustrating…” (Linda)* |
| [13] | *“Dad had gone from being relatively independent I guess and functional, to now coming home with two carers a day calling in… and the idea of someone coming into his home with a mask, he couldn't comprehend that. He had no understanding of COVID despite the fact he had it. ‘Why were these people coming in and why were they wearing masks?’. It was very distressing for him…” (Carol)* |
| [14] | *“It was quite frustrating that if he wanted something, like tea, or food, or … he'd want it there and then. He didn't understand. […] Like, what I thought was, ‘if I got that out of the way, his routine, then I could sit with the kids...’. But it got to the stage then where… he was interrupting unintentionally… he wanted me to, to be with him. […] Like, I've seen myself hiding in the front room, behind the door, eating the bowl of cornflakes… […] And the kids… they were saying to me ‘well, if you're not busy with Grandad, can you do this homework with me?’, because I always was saying to them, ‘I'm busy with Grandad, I'll do it in a minute…’.” (Linda)* |
| [15] | *“Even simple things as I said like going to the cinema… these are our outlets… […] and it was the little things we missed…” (Carol)*  *“My husband and I go out every day for a coffee […] and the cafes were closed… {LG}, the cafes were closed! And we were just drinking out of a plastic cup in a car.” (Susan)* |
| [16] | *“The hug and the shake is a big thing… it’s something we would’ve always had… so she always had it. And she couldn't grasp that I suppose at the start of COVID… yeah.” (Mary)* |
| [17] | *“Whereas with my two friends, both their parents have dementia, but I didn’t see them because of COVID, but both their mums got very aggressive, and I suppose because of COVID we never got to sit down and talk about it…” (Mary)* |
| [18] | *“I lost social contact with my family, with people from the outside. Hmm… my life was one of repetition. And while being isolated, which resulted naturally in loss of social contact, there was loneliness…” (John)* |
| [19] | *“Like, even going to the doctor's appointment, like a simple UTI was gonna put him into a delirious state quite quickly, and you’d tried to get a doctor's appointment and it was just so impossible... […] I just think I felt totally helpless and I definitely feel there was times we were totally bewildered by it all…” (Carol)* |
| [20] | *“When I had no carers coming in… […] I had none of these lovely, lovely people, these human beings that are so compassionate and sensitive coming into my house.” (John)* |
| [21] | *“I did learn that there is a dementia cafe, but I think that was shut down again because of the COVID… I don't know if it's back up and running or not. But I would go and sit in that and I'd like to see… I’d like to talk to others…” (Susan)* |
| [22] | *“It was ok, like, it was easy enough… […] But I always thought they would’ve had a better idea of how [names care recipient] was if they saw her in person…” (Michael)*  *“So the phone calls were good, they’d always get back to you, but they couldn’t really see how he was… […] He didn't really engage… It was more me ringing than [names care recipient] having a consultation... Whereas in a one to one he would be good…” (Teresa)*  *“Everything was virtual and you can't do a proper assessment virtually… […] not that I wanted that cause it doesn’t give a true picture of the person…” (Carol)*  *“But, she wasn't understanding it… she couldn't understand the whole screen... even, you know, the phone. […] But yeah, it was the way it had to be done. […] And I'm so appreciative that they were there from the very start. I don't know where I would’ve been if that technology wasn't there.” (Mary)* |
| *Being prevented from caring for a loved one* | |
| [23] | *“For Mum, it must have been just so confusing that she didn't see any of her family members. […] But that was quite stressful for us, not knowing how she… like, we were given updates on how she was, but just emotionally, we didn't know how she was. So that was a difficult time for us...” (Ann)*  *“Mum would have been threatened not seeing me… […] I was angry because I kept saying, ‘this is my mother!’, ‘bloody COVID, this is my mother, I’ve got to go in!’.” (Susan)*  *“So I found that very stressful. It just seemed that I couldn't do anything for her. She was up there, and she wasn't even great on the phone […] I found that very very hard altogether... […] I don't actually know how she was all that time.” (Michael)*  *“Dad was extremely distressed… Like, the phone calls from him would average maybe 15 to 20 phone calls and you couldn't physically go in to him... He was ringing all the family… he was looking to come home, he was looking for someone to come and get him... […] It's very frightening watching your dad in that situation and then not being able to go in and comfort him or help him, you know?” (Carol)* |
| *Lockdown as a time for opportunity* | |
| [24] | *“During COVID, too, I looked at the house, and it was a horrific house! […] So I said ‘Jeez, why not open up the house?’. So it was [names care recipient]’s Alzheimer's if you like, and COVID, the darkness of COVID…” (John)*  *“I was planning to start a business, so I had lots of time to do that as well” (Linda)* |
| [25] | *“It was nearly a novelty for them [the kids] to be outta school… and we were doing different activities every day that you'd never get to do […] And they were very close to Dad and you could ask them to sit with Grandad […] they’d sit with him, dance for him… […] Now, the kids were brilliant. They knew what was wrong with him… And the lockdown had them to understand more. […] They knew how bad he was, and then when he went into the home, they didn't feel that loss because it was nearly like they really understood how bad he had got...” (Linda)* |
| [26] | *“I didn't find COVID too bad, to be honest… we just slowed down… […] The truth is that his dementia wasn’t as bad at the time… […] We had the house recently done […] so we had space. We had the garden, and the weather was lovely. And we just pottered around. […] We could sit out there. We could snooze out there. If we felt like cutting a wee bit of grass, we'd cut a bit of grass, and potter around, and rest. And potter, and rest” (Teresa)*  *“But no, like, life went on as normal… The only thing is that we couldn't go anywhere... […] But we would go out and sit outside together, and would read the paper... […] And went for a spin […] we did things like that, you know?” (Michael)* |
| **Transitioning out of lockdown** | |
| *Regaining freedom, but restricted freedom after all* | |
| [27] | *“And I went into the gym […] I did all the things you should do but I refused to let COVID direct my lifestyle totally. […] I mean, you had to be wary of it for [names care recipient]’s sake and my own sake. […] So I was afraid of COVID from that point of view, hugely afraid of COVID from that point of view.” (John)*  *“I got to a stage where I was meeting friends for walks when it was okay to do so. […] I actually was still quite careful. I wasn't really keen on going out too much and too early, and so I didn't really… […] I still felt that because COVID was still there, we really needed to look after Mum and Dad and make sure they were safe...” (Ann)*  *“If I was bringing her anywhere, even to today, I constantly sanitize the hands. […] Because she has no understanding, she could have walked in here and she’d be touching and… No matter where you brought her… […] people she wouldn't have seen for a while, even in the hospital, she was going over trying to shake hands, and we were trying to explain ‘you can't do that now’. And that's hard for them… you know?” (Mary)* |
| [28] | *“I was worried… […] I'd be very careful and they were very careful… But yeah, it was a huge help having them come in to help with his personal care. A huge help.” (Linda)*  *“And we weren’t worried about people [carers] coming in… Not at all. We knew the parents were wearing masks and using the gel, and I think Mum enjoyed somebody coming in as well and having that bit of interaction.” (Ann)* |
| *Being in a lockdown of one’s own* | |
| [29] | *“I mean, lockdown was actually just a bit like now {LG}, I still can’t go anywhere… […] It all seems… it doesn't seem any different now or then…” (Michael)*  *“But it's only as he’s progressed... […] Now, some days I don't get away cause he's agitated. Last week, last Monday… he wouldn't let me go. He put a plant down in front of the car so I couldn't get out... So I said, ‘okay, come on with me’. And he got extremely agitated and upset and tried to get out of the car when I'm driving… […] I find it harder now than I did during COVID, cause everybody was lockdown then…” (Teresa)* |
| [30] | *“[names husband] was brilliant. I could stilFl go out with my friends or whatever, but I spent my whole time going, ‘right, I'm just gonna eat this and have one glass of wine and then go’. So I couldn't enjoy myself when I did it. […] And then it would get me to the point where I just didn't bother going anywhere… […] not that [names husband] ever minded doing it, but I couldn't… I wasn't enjoying myself. […] The hardest thing for me was family not calling and offering to help… […] I was angry with them… even to take him away for an hour! Cause [names husband] needed his time too… […] Because I felt guilty for leaving [names husband] here because my family wouldn't help!” (Linda)* |
| **The present with COVID-19, but mostly with dementia** | |
| *Dementia, a disease that does not pause* | |
| [31] | *“And it did seem at one point like, ‘this is not getting any better… what are we gonna do?’ […] Every aspect of life has changed. Like I just feel there's no… carefree time […] Our family life has definitely changed… My son's family life has definitely changed… […] It just seems like sometimes there's enough a lot of irons in the fire and there's always something every day with Alzheimer's... And I love my daddy dearly and I wouldn't change it for a second because he's here and losing a parent is terrific, and the fact that my daddy's here, thank God he is, but it is hard…. […] It's that fear and anxiety the whole time, ‘what's going to happen?’, ‘What's next?’…” (Carol)* |
| [32] | *“I don't know… I suppose it's different… The person I love is here, but she's not always… She doesn't talk very much sometimes… we never have the kind of conversation we would’ve had before...” (Michael)*  *“It’s like you're not really a couple anymore… I mean, you are, but everything changes… The relationship is completely different because you’re a carer not a wife…” (Teresa)* |
| [33] | *“Like, she could be sitting here and there'll be nothing there, and she’d say ‘what's that there?’, and she sees something that isn't there…. I find this difficult... […] And then I get so insistent that something isn't there, you know? […] I know I shouldn’t do it... but I'm not sure what I should be doing at that stage… Sometimes it's my reaction more than her reaction, you know what I mean?” (Michael)*  *“Like, I'm not medical… I have no medical training or anything… so you're scurrying around in the dark really… Because you don't know what he should be going through or what he should be experiencing…” (Teresa)*  *“There was days I walked away crying because she was angry, but I don't know whether she was angry with COVID, society, her own kids… I don't know… […] So… I suppose mentally, yes, there were stages it was draining because I didn't know what to do for her. […] I wish I could do more… I wish I could do more for her when she's like that, and I can’t… You’re… It’s… I suppose for a while… {BR} I don't know how to even explain this… I'm standing outside watching her being lonely, or confused… I don't really know.” (Mary)* |
| [34] | *“Like that, I was talking to a neighbour and he cared for his father in law, and he asks me ‘are you not afraid she is going to leave the house?’, and I say ‘no, I’ve got the alarm on… they’d contact me if the front door opens’. […] So I said ‘no, no, no, she is fine…’, but then I’m thinking ‘Jesus, what if she is not…?’.” (Mary)*  *“You just feel like you're under the looking glass the whole time. People are looking at what you're at the whole time and it's like, ‘we're trying our best’, like we really are trying our best.” (Carol)* |
| [35] | *“I was told by the nurses that it really wasn't sustainable to keep him here... But I didn’t want to organize getting him into a home before Christmas. I would’ve… It’s just… the guilt… […] It was nearly a sense of, ‘well, look, I can mind him. People are telling me it's not sustainable, but he's fine. He has a lovely place here’. And at the back of my head, ‘there's no way I can do this…’ […] And it was, it was very difficult putting him in. But, the relief… I know that's an awful thing to say… but the relief that I could actually even have a cup of tea in bed in the morning at the weekends… […] But then you're kinda going ‘I shouldn't be feeling like that…’. It really did guilt me. […] But I made the right decision, definitely, because my own head was suffering even though I didn't realize that...” (Linda)* |
| [36] | *“Nobody ever told us, home is never home. That's the biggest problem with dementia that I've learned. Home is never home. […] She says, ‘I'm going nowhere. I'm staying here. I'm staying here in my own house!’, […] and then she’d look around five minutes after and she says, ‘when you're taking me home, will you take those ornaments there, and them pictures? They don’t belong to this hospital’. […] And every day since she's come home [from respite], ‘I want to go home’. […] It’s all ‘go home’ with dementia. And we know now that's one of the symptoms, ‘go home’. […] We're learning all this, and I am in the process of getting her in a home full time. And there will be no guilt. There will be no guilt this time because I think Mum, she needs that security 24/7 that we can’t offer. […] Like, my mother said to me she wanted to die in her own bed, and maybe that haunts me a wee bit… maybe I'm just being that wee bit selfish in thinking that I have to keep Mum here if she wants to die at home… but that's just not possible, you know?” (Susan)* |
| [37] | *“My daughter keeps saying, ‘Mum, you're not going to be able to care for nana the whole time’… And… I don’t know… this probably sounds awful, but my thought would be that she just goes to sleep… {BR} … (interviewee cries) … I’m sorry… […] that’s probably a big fear… sorry … (continues to sob). I rather she goes in her sleep than get to the stage where she has to go to a nursing home… that’s probably what it is… It's probably a big fear of me. Because then I feel I failed her…” (Mary)* |
| [38] | *“And she is never going to a home. No matter how bad she becomes. I was determined for that from the get-go. Absolutely no way would she ever go into a home. […] I know that a lot of nursing homes do great jobs and are great, but […] I think the homes, nursing homes couldn't possibly provide this type of care. […] Now, as soon as the carers are finished, I'm inside talking to her. I'm bringing her in to sit with me, to look at television. I'm taking her, I lift her into the car if I can and we go for a spin. And she loves just looking around. She wouldn't get that in a nursing home.” (John)* |
| *‘Takeaways’ from the journey* | |
| [39] | *“I would have always been a hugger or a kisser with my mother, but as a teenager you just kinda fall away from that. Whereas now I always give her a hug or a kiss. Since COVID, when we didn’t have that, we weren’t allowed do that, every time I go into her house or when I walk away now, I give her a kiss and a hug. And it can be four times a day I go over, I give her a kiss and a hug every single time. […] Probably with COVID we really appreciate all the more every day we have with them… […] But yeah, that's probably one of the thankful things to COVID, that I'm not afraid to do that.” (Mary)* |
| [40] | *“I got huge respect for people. The help I got from people was incredible. Neighbours were all over me. Strangers would come up and… and… {BR} ask if I need a lift with her... (interviewee snivels) … {BR} so really it was very good for me because… […] I taught children for 50 years. I love teenagers, teaching them and so on. I always got on great with them, […] but I never had such a relationship with adults. […] And the carers… the respect I have for those human beings who are badly paid and they come in and they make her feel like a special person. […] And again, she's violent, aggressive and verbally insulting them {CG}, and they talk to me, they boost up my morale... […] They're providing caring necessity, physical caring necessity, but they're also talking to her, but they're also talking to me and that's very important for me.” (John)* |
| [41] | *“The only thing is, I've spent more time with my father in the last two years than I have probably my whole life. […] And I think the last two years, like, this little human has come into the world and she has the most unbelievable relationship with her grandad. And I guess if Dad didn't have Alzheimer's, he wouldn't be as idle as he is and he probably wouldn't have the time for that relationship. And it's definitely a unique little friendship they have.” (Carol)* |
| **Looking into the future** | |
| *Embracing COVID-19* | |
| [42] | *“And also, there’s a worry there cause like, we’re heading for the winter… and it’s just like, is it all going to happen again or… do you know what I mean?” (Mary)*  *“COVID can come again, I don't mind, I’m not a bit worried about COVID, not a bit worried as long as I don't get it. And I take every precaution, but I'm not going to over isolate myself. […] I'm conscious that with [names care recipient], that I can’t afford to get COVID, so I don't put myself in the danger, but I'm not going to hide and hide away in order to avoid it… […] I think COVID is a threat, but as long as people are sensible, I don't think they should be in any way fearful of COVID.” (John)* |
| [43] | *“Assuming that we don't get a very bad dose of the COVID again, we’ll hopefully be ok… I mean, most people I know who got COVID got over it very well. I mean, there’s one or two I know that have had chest infections… or there’s all these people who say when they got the vaccine, they weren't feeling well after… But we got our vaccines, we've got everything.” (Michael)* |
| [44] | *“Mum went into the nursing home for respite […] and they had massive glasses erected, and we came in from the outside and we sat on a chair and this big glass panel, and Mum was behind it with the mask on, we all had masks on, and she sat and looked at us, and she kept knocking out to the glass and she put her hand up a few times and she didn't realize it was a glass. I don't know… like, she was putting her hand out to us and she was hitting off the glass... I found that traumatic… […] She was very distressed, and she couldn’t have any of us touch her or hug her… […] I’d leave stressed, thinking of her, you know? […] The only time I would think about COVID now is if she goes into the nursing home and there is another outbreak… […] Hopefully it won't to the extent it came, but if it did come… {BR} it would be at the back of your mind, you know?” (Susan)* |
| [45] | *“You look back and you think, ‘God, did that really happen?’, ‘Was that period actually real?’… And it was so hard for so many, but I think for us, we just seemed to have been struggling our way through it… […] I think the last two years have probably been, with the exception of [names baby daughter], have been the worst two years of my life. I don’t think I could ever go through it again… […] And I think we're definitely… fear is probably driving us towards the vaccination...” (Carol)* |
| *The true needs* | |
| [46] | *“But the only way that I can explain this for myself is that, I was going around, still am, with a big L on my back, learning what is dementia. Nobody had ever sat me down and said, ‘this is what dementia does to a person’ […] Whereas, like, if you were having a bad day or something like that, if you could pick up the phone to like some sort of helpline for dementia and say, like, ‘is there anything that could alleviate this or, assist me with this?’ […] Like a helpline dedicated for carers… not for the patient, for the carer who's looking after the person with dementia, and to say ‘you are human, you are valuable and things will get okay’. That's all you need.” (Susan)*  *“It would be good for society to have a helpline for carers of dementia… Because like that, even though it's a couple of years now, I'm still new to this. I still don't know what's ahead of me. And I know I don't know… […] And also being able to talk to someone who is going through the same… and it’s not in any disrespect, but until you “where my shoes”, you don’t really know…” (Mary)* |
| [47] | *“But one of the support areas we had, there's a place in […] where there's a lady who gives advice to families who have a parent with dementia. So early after Mum's diagnosis, we heard about it through a friend and we went to as a family. […] So that was very useful. And I don't know, if our friend hadn't told us about it, would we know about it? So that was very useful.” (Ann)* |
| [48] | *“And I think we all need to be educated and we all need to prepare for our own futures, and we all need to know, because your partner could get it, I could get it... We need to be educated and there needs to be more out there in the public domain. And it doesn't need to be a stigma. People should be well fit to live with it, you know?” (Susan)* |
| **A word on coping** | |
| *Managing it all as best one can* | |
| [49] | *“I think I worry in advance of things happening. But when they actually happen, then I say, ‘all right, let's tackle this. Let's do something’. Be proactive about it.” (John)* |
| [50] | *“I like being kept busy and I have to be doing something the whole time. That’s what helps me. […] I never think about it. I just keep going, keep going. I always say, it's like this mental block goes up and you just keep going.” (Linda)* |
| [51] | *“I suppose I did get some fun out of it. And, you know, ‘if you don't laugh, you cry’, that's what I always say. And sometimes […] he might open his wallet and take a ten euro note and clean his nose with it. And sure, the kids thought that was hilarious, and I would laugh too! […] But we weren't laughing at him, we were just laughing along because it was… it was life now, that was what he was going to do...” (Linda)* |
| [52] | *“My mother often said to me ‘I’m sorry I’m a nuisance’, and I said ‘You are not a nuisance. You held my hand making sure I didn’t run out on the road, I am holding yours now’, I said ‘It is my turn now, and I am honoured to do this for you’.” (Mary)*  *“And I wouldn't want people to be feeling sorry for me. I think it's… I think it's an honour, really, to be able to help somebody the way she is, and especially when it's your mother, you know? Your mother is your mother and you can’t change anything about that. And I think when I look back, I would say she’s done a lot for me and it's my turn now, really […] I don't look upon it as a burden… I kinda look upon it as a privilege, really, to be able to do it and to look after her.” (Susan)* |
| [53] | *“It's the process that we all go through in life, and every day is a new day, and you say it to yourself, ‘what will the day bring?’, but you seem to get through it. You get through it. And I feel God is good to me. I feel… because I feel that… I feel that I will be gifted in other ways for looking after Mum. I feel special things will happen to me and that's the way I look at it.” (Susan)* |
| [54] | *“But as an Alzheimer's carer, I think being a carer has been good for me […] because I'm not selfish looking after myself, I'm looking after others, her in particular, who deserves it because she's a far better person than I'll ever be. […] And it's very rewarding, extremely rewarding, when you get the recognition, as I have gotten the last month in particular, that she actually slightly understands what's going on. I feel I'm a team with [names care recipient]. It's not me as a carer. We're together. She's opened up a new world for me. I've got enough a lot from this and I'm not dwelling. […] It was the world's worst experience to have the two catastrophes in your life, COVID and the Alzheimer's, all at the same time, and all hitting two unknown troops, thrown at you at the same time. And yet the dangers of each of them turned out in actual fact… hmm… I think they made me stronger.” (John)* |
| [55] | *“I've been through so much in my life that I think for COVID, it just didn't bother me too much. […] I feel that if anything else was thrown at me, I'm probably in a calmer state of mind, and I think that comes from the vast experience of my own personal life […] And sometimes a very bad experience can teach you enough a lot of positive stuff in your life and that you can cope much better.” (Susan)*  *“But I think what I just say to myself is ‘I'll take it each day, I won't look towards that time. I won't look towards it and go back’. And if I look at the past, I will say ‘I learned from the past and we can only stay in the present moment, one day at a time. We can only stay in the present moment and do the best we can. That's all we can do. Nothing else can be asked of us’, you know?” (Susan)* |
| [56] | *“And wondering ‘when is this going to lift?, Is it going to be like this for a long, long time?’. You'd get down thinking about it. But you could only just keep hoping that it's going to move on […] And I turned that around and I said, ‘we'll get nearer to it lifting’. I turned it into a positive {LG}, and I said, ‘This will lift. It's not the end. It will lift’. And it did lift.” (Susan)* |
| [57] | *“I think when Dad came home from hospital, I was off for a little while with bereavement and stuff… and Dad was home and I think we were just on autopilot like…” (Carol)* |
| *Note*. For the purposes of clarity, the following symbols have been used in the transcriptions to describe noises made by the speaker: {LG} = “the speaker laughs”; {BR} = “the speaker takes a deep breath”; {CG} = “the speaker coughs”. | |