



'Mum doesn't understand coronavirus or why she can't have visitors'

Una Caulfield reveals the challenges in caring for her mother, who has dementia, during lockdown, writes **Eva Hall**

When Una Caulfield watched Queen Elizabeth make her coronavirus speech, she couldn't help but think of her own mother, Mary,

who is just three months younger than the British monarch.

"The Queen was so with it and I felt quite sad about that because I haven't seen my mother like that for years," says a tearful Una.

She has been helping to care for Mary (93) since she was diagnosed with dementia seven years ago.

Under normal circumstances, Una says she's a positive person and usually finds caring for Mary very manageable. But the circumstances we all now find ourselves in are far from normal.

"Mum doesn't understand coronavirus. She doesn't understand why she can't have visitors and basically what I'm telling her is 'you stay there, you can't go out, there's no more daycare, the kids can't come in and sit with you', and every day I feel like I'm having to be mean," says Una.

Since Covid-19 took over our lives, the Alzheimer's Society of Ireland's (ASI) dementia advisers have reported an increase in responsive behaviour from people with dementia. Behavioural changes such as confusion,

paranoia, delusions and agitation have all been noted.

Mary lives in a granny flat off Una's house in south Dublin. Una, who has been temporarily laid off due to Covid-19, resides with her husband and two grown-up children, the three of whom are now working full-time from home.

Mary had carers tend to her three times a day prior to Covid-19, but now, for her mum's own safety, Una has made the decision to stop the carers visiting and taking on the task of caring for her by herself.

"I understood that there wasn't full, proper PPE for carers, so we decided that it would be in everybody's interest that they didn't come, because they would be seeing other people and then coming to mum and putting all of us at risk," says Una.

"So I'm now cocooning as well as looking after my mum. My husband does the shopping and the kids go out for exercise once a day. I haven't been outside for a week."

As well as this, Una is caring for an increasingly fragile Mary, who is still recovering from a broken leg after a fall in January.

"She was in hospital and needed surgery for the broken leg," says Una. "She was supposed to be non-weight bearing, but because of her dementia, she didn't understand that, so she was in hospital for 70 days."

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DEMENTIA TIPS

- If a person with dementia approaches you during social distancing, smile, step back and remind them about social distancing. Don't get annoyed or become aggressive.
- If you are cocooning with a person with dementia, distract them with an occupation if they become agitated. When you're occupied, you're less likely to be anxious.
- The person with dementia will need to be reminded they have to stay indoors. Remind them gently, try to keep your patience.
- Don't ever tell them, 'I've told you that before'. If you're finding it getting too much for you, take yourself out of the room, step out for a minute, give yourself a moment to relax again.

Visiting restrictions at the hospital meant Una and her family couldn't see Mary for the last three weeks. She is now home with a Zimmer frame, but Una says she can notice a huge difference in Mary's mobility.

"She is significantly weaker than she was back in January. When she got back home, she just assumed that she could do what she used to do. But with the Zimmer frame, now she can't make a cup of tea or take a drink and bring it with her to sit down because she needs her two hands on the Zimmer frame. She's not really able to do much for herself."

Una has been forced to lock the door in Mary's granny flat, which leads to steps to the back garden, to prevent another fall.

"She hates the fact that the door is locked and gives out about that," adds Una. "I find myself having to make tough decisions for her safety, but it's hard to get that across. I'm just trying to make sure that she's safe because I know that if she has another fall and she goes into hospital, I may never see her again. All those things go on in your head."

"I feel guilty every day. I feel I'm being mean in restricting her or saying 'you can't go out' or 'you can't do this', because she doesn't get it."

"I take her out to the front gate and back each day. I can't bring her down the back garden because there are too many steps."

As Mary's dementia is at an advanced stage, Una visits her every hour.

"Every time I go into her, she asks 'why won't you sit down? Why won't you stay?' and I might have just been with her five minutes ago, but she doesn't remember and she's giving out that she hasn't seen me all day."

Maeve Montgomery, a dementia adviser with the ASI, advises anyone caring for a person with dementia to try to distract them when they become agitated.

"All you can do is gently remind and

distract," says Maeve. "Try to keep your patience. It is hard — this is not an easy thing, we are all human."

"If you have somebody constantly asking you the same question over and over again, that can be utterly exhausting on your whole emotional well-being."

Maeve and the ASI have developed tip sheets with activities that they can email out to carers and make available online for those in self-isolation with a person with dementia.

"It might be looking at a photograph, colouring in a picture, folding laundry, matching socks — we have lots of ideas."

Because Una won't leave her house for fear of picking up the virus and potentially passing it on to her mum, her social life has been impacted even further than most of us, who are still exercising within a two-kilometre radius.

"There's no win in this for me at all," she says. "It doesn't matter what I do or the fact that I've given up my ability to go out for a walk once a day to try and look after her — every day she doesn't get it."

"I feel a huge sense of responsibility because I'm not sure everything I'm doing is right. I'm trying to keep her safe, but I'm keeping people away from her. I don't think she'd survive it [Covid-19]."

For others with dementia, such as those living alone, social distancing guidelines could be something they have forgotten about due to short-term memory loss, says Maeve. She's advising the public to "be kind" if someone approaches their space while out.

"For those with short-term memory loss, if they saw

someone they knew, they'd walk up to them. They wouldn't remember that

you're supposed to step back, even in shops because it's not a natural thing," says Maeve.

For now, Una will remain indoors, cocooning with her mum. "The thing I need is help or somebody else to take over for a while, but that introduces a risk, and I'm trying not to

do that.

“I worry for the future as to how I’ll cope. Hopefully when things calm down, I can go back to work. But I can’t do that without the carers being reinstated. I’m just not sure what’s ahead for us all.”

For more information on tip sheets and other resources on dementia, visit alzheimer.ie. For more information on cocooning during Covid-19, see HSE guidelines at hse.ie.

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Una Caulfield is coccooning with her mother
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