



Personal Outcomes Stories during COVID: Phase 2 understanding from experience

A personal family story – Lockdown with Betty - by Denise Noone, Freelance Photographer and carer

Denise 57 Freelance Photographer, Ian 57 Plasterer,
4 offspring:

Ethan 24 Bar manager; Alistair 24 Student/supermarket assistant;

Lili 21 Student/waitress;

Ruby 17 Student/waitress Mother/Grandmother Betty 80 who has dementia

What has continued to help keep a focus on what matters for people during the pandemic?

I took care of my mum, Betty, who has dementia, with the help of my family for the first three months of lockdown.

I have MS and after three months I needed a break. I haven't got a spare room, so mum has to share with my younger daughter. So as much as I needed a break, the whole family, especially Ruby, needed some respite from the intensity of caring for someone with dementia.

So my sister came up from Kent to collect mum to take her back to London. It is not ideal because mum should be settled in one place.

Are there changes that seem to be lasting longer term and are there things that have slid back to old ways of doing things?

Mum was fine initially down south with my sister, but it is only my sister, her husband and stepson in the house. They are fairly taciturn people and the way my mum's dementia presents is she seeks constant approval and eye contact. So, with fewer people to share the care and give her attention she was quickly frustrated and my sister reported she would hit out at her sometimes. She returned to Scotland after five weeks.

What difference has this made to people?

My sister and I had begun to share care of my mother a few months before lockdown. It became apparent she could not take care of herself after a bout in hospital due to mal-nourishment. We had begun the process of getting social care involved in east London where my mum lives. The area is not affluent and is densely populated so the service is slow and nothing was achieved before the covid arrived.

When mum returned to Scotland for another stint with us, everyone in my household had returned to work and school and were out of the house more often. It took me a while to get back into the swing of things and mum's condition had moved to another level. Her paranoia is greater, so I had to hone my distraction skills and busy her with lots of chores (her happy place) and ironing but finding things for her to do is a chore in itself because her ability is limited. We can have great days with her, but she becomes antagonised at the slightest things and recently, later in the evenings are when she is most bewildered.

I am involved with a theatre company and they were starting a new project making short films (in place of theatre). I had to submit a true-life story to show an interest. I had thought that mum's care would make it difficult to achieve this but I decided that I needed a diversion for my head. Of course, the subject in my story was Betty and the theatre company decided that their first wee film would be hers. I had to spend a few days making images and shooting footage and as mum just likes being occupied, she was very engaged with the whole process of doing tasks for the camera.

<https://vimeo.com/463061735>

How did this make you feel?

I was finding looking after mum intense and when she is here, I get little time to myself and because all the family are busy, I have been missing their full attention and help with mum, that full lockdown afforded. My own symptoms have been getting worse. I have greater weakness on one side of my body and I found I had burning sensations at night in my weaker leg and my walking was deteriorating.

I realise that this situation is not tenable but during this pandemic I don't feel we can consider alternatives. Eventually, mum will go into care but it is not somewhere we going to send her just now because it is not safe.

Meantime at the end of last week, my sister came up from London to collect mum and take her back down there for a while. My own symptoms have improved considerably in the few days since. This is a great relief to me because I had thought the deterioration was permanent. Getting a break is so important.

Reflecting on your experiences what have you learned?

I have realised fully that getting frustrated and impatient with a situation only prolongs it. Betty in particular responds so well if I treat her gently & patiently.

I have learned quite forcibly that the connection between mind and body is stronger than I had understood before. My physical health has so improved as my stress has reduced.

What difference has it made to you to tell your story as part of this project?

It has made me pay more attention to the dynamics within my family and it is cathartic to get it down on paper.