



Avril's Journey

Stroke to Dementia to Care Home

How I went about finding the best care home for Mum...

Friends of the Elderly have asked me to tell mine and Mum's story in order to hopefully help other people in a similar situation. Back in 2017, Mum had a stroke. It was only a little stroke, but a stroke none the less. She slowly bounced back and with the help of our local hospital's Occupational Therapy team, lots of encouragement from my husband and I – and two pills (that we affectionately call her morning anti-stroke pill and her 'not having a stroke at night pill') she appeared to recover well.

However, we soon realised something wasn't quite right.

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Mum, who had always been as bright as a button, began to say that her memory was ‘playing her up’

We noticed that she – almost overnight - became more forgetful (OK, it happens as you get older, but this was different), confused and she started to hallucinate, vividly hallucinate.

Mum was not just seeing things but having full blown conversations with people who were not there. They ‘proper’ conversations about ‘proper’ subjects like shopping, raising children and the news, she’d even stop talking and wait for the non-existent person’s response before carrying on the chat - she even asked me to make them a cup of tea on more than one occasion. As you can imagine, it was quite scary (even sad) to witness.

I took Mum to the **Memory Advisory Service (MAS)** and, after being evaluated, I was told she had Mixed Dementia. They were extremely helpful and gave me lots of suggestions of things to do to keep Mum entertained, active and mentally stimulated and also prescribed Memantine (this one we called her ‘Brain Pill’).

Prior to the first lockdown back in January 2020, we moved Mum in – lock stock and barrel – to live with us. We made this decision for a few reasons. One, it was becoming apparent that she couldn’t properly care for herself any more. Two, we were scared that she’d have a fall and do herself a real damage and three, if the rumours of a nationwide lockdown came to fruition (which we all know they did), we couldn’t see her living on her own, with nobody to talk to, no visitors and no company. Goodness knows what would have happened and what state she would have been in.

When she started living with us, things plateaued for a bit. She was eating well, enjoying my husband’s cooking (I burn water!), keeping active and enjoying living with us. Then, over the course of a few months, Mum started getting up at night, getting out of bed and walking around (well, trying to on her Zimmer frame) which led to falls and a couple of mad dashes to A&E and a few hospital stays.





Unusual behaviours

- Forgetful
- Poor sleep
- Loss of appetite
- Very agitated
- Hallucinating

Mum also began to get very agitated in the evenings (we learned that it is called Sundowning) and not knowing what day or time it was. However, one of the biggest changes was Mum's sleeping pattern. Six nights out of seven we'd hear her talking very loudly and eloquently in her sleep for most of the night, sometimes she was singing and clapping.

We were so worried we contacted MAS again and, after another assessment, we were told that Mum's dementia had deteriorated and she was now classed as living with **Severe Mixed Dementia**.

Following another hospital admission (this time for a chest infection and UTI) we were approached by Adult Social Services who (now I look back on it were right) said we needed additional support looking after Mum.

The outcome of this was that we paid for two carers to come in three times a day to help me with Mum's personal care. I should add here that the Occupational Therapy team were great again and our house became a fully fitted care home with all the equipment Mum needed – everything from a hospital bed, wheelchair commode, rotator and mini lift - which helped get Mum up from bed and her chair and on to her indoor wheelchair. I won't go on too much about Mum's medical conditions that materialised since her dementia diagnosis, as that's a bit too much. Let's just say she became immobile, unable to feed herself and suffered with incontinence.

We wanted to keep Mum with us for as long as possible and continued to try to make every day special and happy in some small way. We always put Mum's needs first, we were adamant that we wanted her to be healthy, happy, safe and comfortable even when she needed more nursing care than she could receive at home.

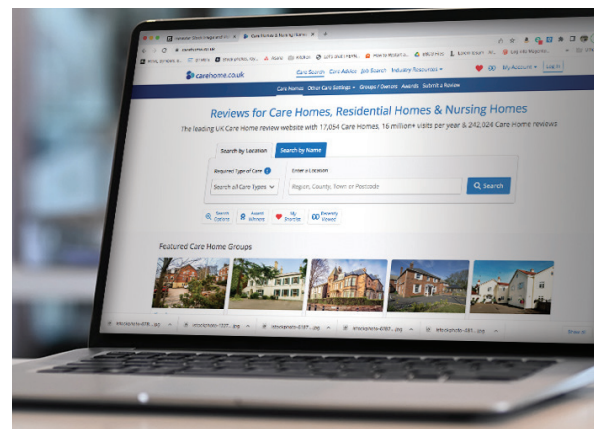
So, with our sensible heads on, my husband and I, who are both Mum's **Lasting Power of Attorney**, knew we needed to think about a care home for Mum and her future medical and dementia needs.

We didn't want to be thrown into panic mode when the time finally came, so started doing a bit of research.

First, I spoke to the carers who came and helped me with Mum. They recommended a few places – and also warned me off quite a few too. I also knew that our neighbour had moved into a care home along the road from us, so thought that might be an option as it was so close. I then visited www.carehome.co.uk and did a search on other care homes near me.

From this, I drew up a list of six care homes that looked promising. Oh my, how wrong can you be? But I'll come to that. I should add here that none of the homes I looked at were Friends of the Elderly's homes. My link with FotE is that they have asked me to talk about finding care.

Before I arranged face-to-face visits at the care homes, I read their **CQC** (Care Quality Commission) Reports and reviews on www.carehome.co.uk. I also requested brochures and visited each home's website to request a call back (if the option was there) to arrange a visit.



Some websites were far better than others. A few were 'clinical' and 'hospital-like' but had good CQC ratings, others looked more homely and friendly, which was nice. One just had an image of the building, an email and contact number. The building looked drab and 'prison like' – who ever thought that would entice potential residents I don't know! I wasn't very impressed, so scrubbed it off my list.

So, I was now down to five.

I received four brochures via email and one didn't even bother getting back to me at all – so now I was at four. If they couldn't even be bothered to send me a brochure or at least call, that didn't fill me with confidence that they'd be able to care for Mum – so they were scrubbed off the list too.

I arranged visits to all the remaining four care homes.

When I spoke to the Duty Manager at one of the care homes, her tone was quite 'off' as if I'd interrupted her and my request was going to be a real pain 'how dare I ask to come and visit.' You guessed it. I politely emailed to say I'd changed my mind... down to three.

I drew up a checklist of things to look out for (even how the homes smelt) during my visit and a list of questions to ask the Care Home Manager or Duty Manager who would be showing me around.



My Checklist

- ✓ CQC Rating
- ✓ Location
- ✓ Accessibility
- ✓ Accommodation
- ✓ Staff
- ✓ Communal areas
- ✓ Daily routine, activities and events
- ✓ Dining - Do they meet the resident's dietary requirements

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I drew up a checklist of things to look out for and a list of questions to ask the Care Home Manager or Duty Manager...

Not questions to catch them out, questions that weren't really addressed in their brochures or on their websites. One that sticks in my head is "On your latest CQC Report, it says your Responsiveness Requires Improvement. What was it that needed to be improved and has it been actioned or fixed?"

I also had a scorecard that covered different attributes of each care home and marked each one out of 10. Things like location, accessibility, the accommodation, the staff, the residents' daily routine, the communal areas and dining, those types of things. To make sure I didn't forget anything, or mix the care homes' scores up, I did this in the car before I drove home after each visit.

The three remaining care homes were all nice in their own way, but one stood out, head and shoulders above the other two.

Why did one care home stand out?

Not only was it a feeling that Mum would be well cared for, loved and looked after, but all the staff who I met were smiling and said hello – it's the seemingly unimportant things that mean the most.

I noticed the staff were chatting and interacting with the residents, the residents looked happy, there was lots of laughing and the rooms were spacious, clean and well aired. The activities timetable was displayed in the reception area and covered a wide and varied selection of things Mum could take part in, they had two on site hairdressing salons and residents get two hair appointments a week and a manicure a week – plus the chiropodist visited every six weeks. Mum is a bit of a fussy eater (roast potatoes never boiled or mash!) but I was assured that all her likes and dislikes would be catered for and the dining room and menu that was on show looked great.

The one I decided to go with did one more thing... they said that when Mum finally needed to move in, I could visit at any time and, as a freelance consultant, I could work from her room all day and every day if I wanted.

As I left, the Manager said, *"When Mum's here, it will be good for you too as you can go back to being her daughter and not her Carer, we're here to do that for you."* That was it, my decision was made.

So very sadly, things took a drastic turn and Mum peacefully passed away. Mum suffered two strokes out of the blue and this time her little body didn't recover. I called the Care Home Manager to let her know what had happened and she was so caring and lovely. It was reassuring to know that even though Mum never left us to move into the care home, it would have been the right choice. It was nice to know that if she had gone into the care home, she would have been loved.

For more information about Dementia Care:

☎ 03305 550 378 🌐 [fote.org.uk/dementia-care](https://www.fote.org.uk/dementia-care)

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