



*"If I only knew THEN
what I know NOW"*

ABOUT



DEMENTIA



By Kirit Thakore

"If I only knew then, what I know now"

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MY MUM

My mother passed away Friday January 3rd 2020, 4 days before my birthday. The night before, when she couldn't remember anything and then out of the blue, she looked over at me and started clapping and singing happy birthday. I asked her who's birthday it was going to be. She smiled and pointed at me.

I was beside her at City Road Hospital in Birmingham, when she took her last breath, a moment that is permanently etched in my mind.

She entered this world on Friday 1st October 1943 and was born in a little village called Gajera, in the state of Gujarat in India.

It was a tough time as she had suffered for many years prior with loss of memory as well as struggling with the deterioration of her physical health. She left 5 children, 14 grandchildren and 11 great grandchildren. Her name is Gangaben Thakore, my sweet sweet mum.

If I knew then what I know now, my memories would not be clouded with so many regrets, instead the happier times would have been at the forefront. I hope my words and experiences will help you with your loved ones.

We had so many good times. Even towards the end, I would take her to the One Stop Shopping Centre, her favourite shopping place. We would sit in the food court outside Greggs the bakery. I would always try and make sure we sat in the same place.

Mum was unsure as to what to have, but I knew what she liked. A cup of tea and a biscuit. She would say she didn't like it, although she had eaten that shortcake biscuit 100's of times. I'd

convince her to have a little piece, as she always said she had already eaten, although I knew that she hadn't. She would take a little nibble and I would distract her and put another little piece on her plate without her seeing and then she would slowly eat a little more. After a while the biscuit was eaten and seeing her do that made me happy. Seeing the blank look in her eyes, like she had eaten the biscuit alone, and like she had no idea who I was, made me sad.

I would talk to her about the shops, which ones had been there for a long time and which ones had recently opened. On good days we would reminisce about the centre and on other days it would be like describing a brand new event. If she mentioned a shop as if it was brand new, even though I knew it had been there for years, I would get excited about the 'new shop'.

I took her to One Stop on purpose. I knew that people who know mum would often pass by, as

this was the main shopping area. I would be keeping a keen eye out to make sure they didn't miss us with the busy flow of people.

Mum was loved and so, when they did see us, they would always come over and greet her kindly with "Hello Gangaben" or aunty or grandma or mum or sister. She was fondly all of these and more. If she replied and addressed them correctly, then again, I was happy.

In conversation, mum would mention somebody that was related and ask how they were. The person who had stopped to speak to us would look confused and would say that the person mum was asking after, had passed away sometime ago. Mum, would be shocked and not able to absorb this, as she could not remember this. In fact, she would go through the emotion's of finding out for the first time again. Can you imagine losing a loved one, and then going through the emotions of losing them again and again? She would often say it's not true and I

would try and change the subject quick.

Sometimes, when the person stopped by, I would initially try and get a quick word in saying that my mum is well but she tends to forget. This way, when mum did say something unusual I would quickly look over and signal them to please try and go along with it.

I would then help her sit in her little wheelchair and we would head to the car. On the way back though, on hot days, there was the ice cream van. Again, she didn't want one, but I knew she loved a cone with red strawberry juice on it. I would park her up and go and get two cones.

Once she saw it, there was hesitation in eating it. I would sit mum so that the sun was facing her and she would take in the heat and have the ice cream. I have such wonderful memories of her eating ice cream. I would also take every opportunity to take a photograph and so glad I did as it's these memories that last forever too.

We would get back to her flat and she would see the postman and would say "hello son". He would hug her and say "hello mum". Then her neighbour, Jackie, would pop out and greet her with "hello mum" and mum would reply "hello daughter". My mum was everyones mum.

Once inside, I would put on the TV, make tea and we would settle down watch her favourite program for the 100th time for the 1st time again. Slowly she would drift off to sleep.

She would be lying on the sofa, covered in her blanket. Often, when the grandchildren or great grandchildren would be there, they would all be cuddled there too.

THE SIGNS

On one of my regular visits to my mum's, I noticed that she had left the gas on the stove on. I turned it off, without giving it a thought as it's something we have all probably done. The same with other things that were either left out. One time I went into her bedroom and her bed was not made and I jokingly said that she was becoming like me. To my surprise she was adamant that she had made it and looked a bit confused, even wondering how that could have happened. In hindsight, these were the first signs but at the time I still didn't give it a thought but also because it didn't happen all the time.

Although for years I would always come on Saturday, mum started to ask me what day it was. I suppose this was the first time that I started to question her memory. "She's becoming forgetful", I would say to myself but then make sense out of it by thinking that these things happen with age and so dismissed it.

I also noticed that my mum was starting to lose weight. She has always been tiny but I could notice that she was not looking as healthy as normal. Mum, although a small woman, always had a big appetite. I always used to wonder where she put to it. On many occasions, I would suggest we eat something and she would say she was not hungry as she had just eaten, and as I had no reason to doubt her I didn't take any notice. At the times that we did eat, she would always eat plenty and so giving me no room for concern.

Mum has had severe asthma for over 40 years and also on a number of medications. As she got older she was more susceptible to illness. About 2 years before she passed she was admitted to hospital as she was losing so much weight and had a bad chest infection. During her stay she said she was frightened and wanted to come home. She said that ghosts would visit her at night and that some of the nurses were spirits. Again, we, and the doctor's, explained this as a result of her being ill. I cry thinking about how

terrified she must have been and for everyone to have just written this off so lightly. I still see her scared face looking around the ward.

Because of her deteriorating physical health, we were advised to get a carer for mum. which we did. She would visit twice a day to help out with cleaning and making light meals.

The first time that it occurred to me that it might be a genuine issue is when I got a call from my younger sister. She asked me if I had seen mums gold earrings as she had had a call from a very panicked mum, saying that her earrings had gone. Mum was certain that the carer had stolen them and was being very nasty with her words. This was very unusual as my mum never had a bad thing to say about anyone and would normally talk affectionately about the carers, as she appreciated what they did for her.

A while later, my sister called back, this time from my mums. She told me that the earrings were in my mums earring box. Obviously my

mum had put them in there and forgotten. My sister mentioned that mum was distraught when she arrived and did not believe my sister when she said that the earrings were in the box and that she even accused my sister of having them. Mum was speaking to my sister in a very unusual and quite nasty manner and my sister was in tears, saying that this "just wasn't like mum at all".

My younger brother then also turned up at the flat and also got upset, just looking at our dear frail mum. We all knew there was a problem. Our conversation of how she was forgetting things, her change of mood and behaviour, her seeing things, her not eating and mum just not being mum led to us making an appointment with our GP.

MUM HAS DEMENTIA

Our GP has known the family for over 50 years and he could see the difference in my mum. He suspected dementia from the information we had given him and although mum was totally herself on the visit, he arranged for some special tests where they would determine what type of dementia mum had got and then hopefully they would suggest treatment.

The tests concluded that mum had vascular dementia, caused by reduced blood flow to the brain, which damages and eventually kills brain cells. This can happen as a result of narrowing and blockage of the small blood vessels inside the brain or even with the possibility of a single stroke, where the blood supply to part of the brain is suddenly cut off.

Apparently there are many types of dementia with Alzheimer's Disease being the one that most people are familiar with.

The specialist told us that the early signs of vascular dementia can include mild:

- slowness of thought.
- difficulty with planning.
- trouble with understanding.
- problems with concentration.
- changes to your mood or behaviour.
- problems with memory and language.

These were all signs that we had witnessed with mum.

We were told that it was there was currently no cure for vascular dementia and that there was no way to reverse any loss of brain cells that happened before the condition was diagnosed. Treatment can sometimes help slow down vascular dementia. Why oh why did we not recognise the signs earlier?

We were also advised that in the later stages of dementia mum may get worse, slowly over many months.

During this time they will usually:

- become more frail.
- have more frequent falls or infections.
- have problems eating, drinking and swallowing.
- be more likely to need urgent medical care.
- become less mobile.
- sleep more.
- talk less often.

The heavy blow for us was when we were told that on average, people with vascular dementia live for around five years after symptoms begin. This was hard to take as we knew that the symptoms were visible for about 2 years. We were heart broken.

As we get older, things get taken from us, that's life. What we don't think about, is that even when we are younger, our parents, friends and family get taken away from us.

THE LAST YEARS

Things after this started to deteriorate faster. Unfortunately I didn't take the time to research more. I wish I had spoken to somebody who had been through the experience. Then I wouldn't have so many haunting memories.

My hardest battle with mum was that of her not eating. She was wasting away and I would shout at her for not eating. She would look scared. (I'm crying as I write this). I would threaten that I would go home if she didn't eat and she would beg me not to go (what kind of terrible son was I?). There was even a time when my own children were there and she would not eat and I said that we would all go if she didn't eat. One of the worst moments of my life. I only did this because I loved her so much.

She would nibble a little bit and say she was full, or that she was going to be sick. She would insist that she had already eaten.

If I knew then what I know now then I would have realised that mum really thought she had eaten. She really believed it. If I had just eaten and then somebody tried to get me to eat, how would I feel? If they threatened me with leaving me just because I felt I couldn't eat anymore, how would I feel?

Your loved ones are struggling with this terrible illness and living in a different memory frame. Find ways to motivate them to eat a little. The body's natural hunger will get them to eat more. With dementia, the unwell mind is in control, it controls the body too. It is such a powerful thing, that even if the body is starving it can confuse it to feel as if has just eaten.

Towards the very end, I understood more. I knew mum's favourite eating place and would encourage her to go. It was a small Indian cafe. She would always say that she didn't want to eat and so I would just ask her to come and keep me company. I also told her that the staff like seeing her. Sometimes she would remember them and at other times she would ask "what staff"?

When we got to the restaurant, even before we got in, she would say she didn't want to eat. I told her it was ok and not force an issue. I would order some of her favourite foods. I knew the smells would arouse her taste buds. I knew the sight of all the various foods would entice her eyes. And, I knew the flavours would get her taste buds salivating. As much as her mind was fighting all this, I had my own battle plan. I would put the smallest bit of food on her plate and say "come on mum, have a tiny bit. I know you are full as you have just eaten but join me as I didn't like to eat alone".

As soon as she ate her first bite and went for a second, I knew I had won. Slowly I would add more. Seeing my mum eat so well is a wonderful memory. Why could I have not done that in the early days. Unfortunately more sad memories of eating issues fill my mind than these few good memories.

*Its a battle of mind against other senses, fight it with what you know **now** and what you **now** know.*

I used to stay over and sleep in the living room of the one bedroomed flat. At night, mum would go to the toilet at least a dozen times. 3 doors before the bathroom meant lots of opening and closing of these doors. For some reason, she would flush the toilet a few times. Taps would come on, lights on and off. This would be so tiring for her, and for me. As she got more frail, she would stumble, as she would not switch the lights on, for worry of waking me up, which she had done already. I installed lights that would come on automatically, lighting up her way.

On top of this, she would have the most terrible cough. It would last, what seemed like all night. I would eventually shout at her to drink some water. I could hear her try to contain her coughing for a while but then it would just return.

Ashamedly, I used to stress about ME being more tired with mum waking up, making noise, coughing and lighting up the room. Why couldn't she just get a good night sleep?

If I knew then what I know now. After my mum passed away, and the first time I stayed at the flat, there were no interruptions, no lights coming on, no doors opening and closing, no toilets flushing, no coughing. Without all the disruptions that used to keep me awake, I STILL DID NOT SLEEP. I was waiting for these sounds. I'd close my eyes and suddenly think I heard something but no. I even called out "MUM".

Towards the end, these sounds were the only sounds that made me aware that my mum was alive. What I would do to hear these again?

I could have sat beside her when she was in bed and helped her sip water with honey. Helped her walk to the bathroom and back. All these things we do when they are in hospital, dying, instead of when they are at home trying to live. Nights were the hardest for my mum. If I could go back, I would not worry about my sleep at night, maybe I could have got a few hours sleep in the daytime, but I could have done things better.

Mum used to get very frightened being alone. She would say she sees ghosts and spirits, that people around her were going to hurt her, that people were going to steal from her, she had the most terrible paranoia. She would beg me not to go, or curse me for not coming to visit her. I would tell mum that it was all in her imagination and she needs to stop thinking about it. In fact, I would be so adamant at times that I would tell her to stop talking about it, that the more she talked about it then the more she would think it was real. Sometimes, I would be desperate to get away to get a little peace from it all. My guilt at leaving her was so much.

If I knew then what I know now, I would have realised that dementia takes people into another realm. A realm that we do not understand. A realm that is totally real to the person suffering.

Towards the end, when mum was in hospital, I started to understand and my response to her was totally different. When she would say there was ghost nearby, instead of denying it, I would ask her more about it. Where it was or who it

was. I would even pretend that I could see it. Sometimes I would tell her to try and ignore it because the ghost wants “us” to pay attention to it and that if we didn’t pay attention to it, it would get bored and go. If this wouldn’t work, then I would say that I would go and speak to the ghost and tell it to leave, otherwise I would harm it.

Now, this may sound crazy to you but you have to think from the perspective of the person suffering from dementia. If you really believed you saw something and the world belittled you, saying you didn't, would that not make you angry. So, I had to get involved in this world of make believe. Why? For one reason only, to make mum feel safe and more comfortable. The more I denied it, the bigger the ghosts became. The more I got involved and helped remove them, the more time I got with mum. If I had understood this earlier, then mum would not have spent so much time frightened.

Be the slayer of ghosts and spirits and the hero to the people being attacked.

THEY MAY FORGET BUT WE MUST NOT

One of the things that I will always remember is the phrase “Cup of tea Gangaben?”.

This was said by the many nurses that cared for mum when she was in hospital. Mum would always reply “Yes, please”.

When she was back at home, I would always enter the flat with “Cup of tea Gangaben?” and my sweet mum would reply "yes please". We would have giggle about it. In fact, when I did mum's eulogy, I shared this story and a couple of years later, I remember meeting a friend whose mum was starting to suffer from memory loss. I was sharing some of the things that I have shared with you and he said that he remembered my eulogy and the words “Cup of tea Gangaben?”, were still engrained in his mind.

The first time back at the flat after my mum had left us, I opened the door to what normally was a warm flat to a cold, dark one.

I spoke out aloud, "Hello ba (Indian word for mum)..."

I walked into an empty living room and with tears rolling down my face, I asked "Cup of tea Gangaben?" ...

WE MUST REMEMBER - FOR THEM

We must remember the love they gave to us when they cannot. For us it's a choice, for them it isn't.

We must remember the real them when they cannot remember the real you.

We must remember to let them live in whatever moment they are, and join them there.

We must remember, it is not them giving you a hard time. It is them having a hard time.

We must remember that on some days there won't be a song in your heart but you have to sing anyway.

We must remember that it is not how much you do, but how much love you put in, doing whatever it is that you are doing.

We must remember not to shout or get angry, just agree.

We must remember never to lecture but try to reassure.

We must remember not to ask them to remember, instead, just talk about the good times.

We must remember not to try and reason but to divert their attention.

We must remember to look into their eyes when they are lost and find them.

We must remember to ask for help. Asking for help, helps them too.

We must remember to listen to their stories like it's the first time they are telling you, even if it's the hundredth.

We must remember to make them laugh and help them sleep.

We **must** remember to
find a better way.

*"I know all these
things now, If I
only knew then"*

"Cup of tea Gangaben?"