

IT IS THE DISEASE, NOT THE PERSON

(The personal experience of a care-giver)

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CARE-GIVING

I was the care-giver to my late mother, since 3 decades ago when she started to show personality changes. She passed away peacefully a month ago at the age of 89. Though I knew very well that her death was imminent as she had become a bag of bones, totally bed-ridden, in recent months, I still feel a strong sense of loss. Nothing could possibly have prepared me for that sad moment.

In the 70's our family doctor diagnosed her as going through depression and that it would go off with time, though no time frame was given. **There were no geriatricians, no support group, no literature, no internet to consult. So we just persevered on our own, and learnt from trial and error. It was only in 1994 when former US President Ronald Reagan went public, that we learnt that Mother was suffering from Alzheimer's Disease and that she wasn't mad as in a lunatic, that she was not alone as a patient, and that we were not alone as care-givers.**

It is not easy coming out to the open to talk about my experience without painting an ugly picture of my mother who was in this horrible predicament through no fault of her own. My only hope is that my public acknowledgement can be of help to others in the same situation. WE NEED TO UNDERSTAND THAT OUR PROBLEM IS THE DISEASE, NOT THE PERSON.

DETERIORATION

It was indeed very painful and stressful to see the deterioration of my mother degenerating slowly from being a caring, filial daughter, from being a supportive, selfless wife, from being a loving, doting mother to become an eccentric, self-centred adult, to become an irrational, stubborn teenager, to become a helpless baby, to be served hand and foot over the years.

Two words aptly sum up my lot as a care-giver. They are " TRYING" as in difficult to deal with and "TIRING" as in exhausting mentally, emotionally and physically. With babies and children, each day gets better, with AD patients, each day gets worse

From my experience, AD patients are extremely difficult to deal with. No amount of reasoning can do any good. They are set in their own ways and will not compromise. They lose their feelings for others. I have learnt never to argue with AD patients. Not only do we stress them, we stress ourselves too. The only way is to distract them.

The main problem with AD patients is **FORGETFULNESS**.

Their memory loss is very frustrating and irritating to people near them. In the early years, my mother forgot to be grateful and appreciate each new day. Sunny days were no good. Cloudy days and rainy days were no good either.

She soon forgot to appreciate what she had – a happy family with a good husband and 4 daughters who were all university graduates by then, well-behaved and who never gave her problems of any kind. Nothing seemed to please her. Whatever we did did not go well with her, so much so that Dad referred to her as Mrs Thatcher, who was then the leader of the opposition party in England. (From 1975 till 1979 Mrs Margaret Thatcher was the leader of the Conservative Party in England. She became Prime Minister from 1979 till 1990.)

Very soon she forgot to act with decorum. She would ask the same irrelevant personal questions over and over again when visitors came. She would stare at people in public openly, and would make embarrassing remarks loudly.

She forgot her duty as big boss in the family. She forgot how to do marketing, how to give instructions to the maid.

Surprisingly the first important person she forgot was her mother, whom she used to love dearly. Then, of course, over the years, she forgot all family members and friends.

When my mother became a grandmother herself she forgot the expected role of a grandmother. She forgot to show her grandchildren love. She did not dote on them.

She forgot the importance of cleanliness in the house. Newspapers, bottles and other thrash could not be disposed of without fuss.

In later years, she forgot the importance of her appearance. She would only wear 2 sets of clothes until these were tattered and torn. The rest would be locked in her cupboard untouched. We felt very sad but there was nothing very much we could do. What was frustrating was that she would demand new clothes. These would then be locked away. Then she demanded new bras, panties, pyjamas, towels, in turn and these again would be stored away under lock and key.

She forgot that things in the house had specific places. Whatever she could lay hands on would end up in her bedroom. These included nail clippers, tissue paper, rolls of toilet paper, biscuits, letters not addressed to her, forks and spoons, creams, ointments, Panadol and other

medical supplies. I found out the hard way only to remove a few items, not all the items at one go to avoid a showdown.

Then she forgot how to bathe properly. She would occupy the bathroom for two to three hours on each occasion, and she had to be treated by the dermatologist because the corners of her finger nails were rotting through excessive exposure to water. Later it was a different scenario. She would emerge from the bathroom, after two or three hours, not bathed and wearing the same clothes. From then we had to bathe her, despite a lot of resistance and protest.

Very soon, she forgot how to address her toilet needs. We had to use diapers on her. These would be pulled off and thrown away, together with the contents. She was bed-ridden the last 2 years of her life and then we had a different set of problems.

She forgot how to appreciate tv programmes and soft music. She would talk on good days, uttering disconnected things of the past, with no two sentences related.

Mother used to love food. At one stage she forgot that she had had her food. She would accuse us of not providing her with meals. Then food had to be cut fine, then blended and later she only took clear soup. She forgot how to eat. So we had to feed her teaspoon by teaspoon Given a straw, she forgot how to suck. On good days, it took an hour to feed her. On bad days, it took hours as she just refused to open her mouth.

Another serious problem was **HALLUCINATION**

In the early years, she would insist that baskets, wheelbarrows were flying all over in the garden. Then strangers were walking through our garden walls, through, mind you. (Reminds me of David Copperfield, the illusionist.) It was quite scary as she could describe vividly what she had “seen”. It must have been real to her.

At one stage, mother complained of aches and pains all over. Almost all were imaginary. **She was attended to by many specialists in town:** the consultant physician, ophthalmologist, orthopaedic surgeon, dermatologist, orthodontist and they found nothing wrong with her. **So she ended up being attended to by a psychiatrist.** At the beginning, we left her medication with her. Imagine the shock I had when I found hundreds of little bottles of tablets, ointments, eye drops untouched and unopened in her bedroom drawers.

Mother could at one time describe vividly her encounters with her ancestors, who were all dead and gone. I was quite frightened initially as I believed that the end was near. But her hallucination went on for years. She would insist that her father came to visit and sat on a

particular chair and that they had a lovely time. Then on another occasion her mother came, then her brother. At first I told her that they had died. That made her very unhappy. Then I realized it was better go along with her and agree with her.

MY BELIEF

I strongly believe that life on the part of Mother had not been fun. With her forgetfulness and hallucination, she must have been very confused. It must have been terrible and frightening not being able to recognize or recall vaguely familiar and yet unfamiliar faces, vaguely familiar and yet unfamiliar things and vaguely familiar and yet unfamiliar events. It must have been stressful to have these vaguely familiar and yet unfamiliar people milling around her, forcing her to do things, forcing her to remember things that she was not capable of. Life must have been tough for her, with no one to understand her, with no one to turn to for help. She must have felt alone, lonely and frustrated.

MY SENTIMENTS

Though life had not been very pleasant for more than 3 decades because of Mother's condition, I have no complaints. I would do it all over again if given the chance. She was an excellent mother who had our welfare at heart all those early years in her life. She and Dad gave us their best enabling my 3 sisters and me to achieve our dreams to become what we are today.

Moreover I have lovely memories of her to fall back on to see me through. In actual fact I begged, not asked, to be in this situation. My siblings had told me to leave my parents in their own home. I could not bear to do that and moved them into my home when my husband and I bought our own house in the early 80s. Dad passed away in 1987. I am grateful that Mother had been with me until a month ago. I have no regrets. I think it is only proper that since Mother brought up her 4 daughters well, she deserved to be treated well in her old age. Mother gave us her best. I should give her my best too.

BLESSINGS

I am blessed that Mother was never been abusive, aggressive or vulgar in action or in words. She had been a very gentle lady all her life. She was just uncooperative and negative when AD set in.

I am blessed that Mother never ventured outside the house and got lost. She had very often in the past, peeped from the front door but the mere mention of the word “Japanese” would bring her hurrying back to her room instantly. When she was mobile, she would wander from room to room, seemingly looking for someone or something, inspecting Milo tins, garbage bins, etc.

My husband has been very supportive all these years. In actual fact, his name was the last name Mother forgot. She called every one by my husband’s name for years. My husband used to pamper her with afternoon snacks whenever he came back from work when mother was able to enjoy food.

My two daughters were equally fond of their grandmother. Whenever they were in Penang they would sit with her, hold her hands, stroke her back, listen to her incoherent stuff, talk to her, feed her.

I am blessed that my siblings did not interfere with my decisions. Being in Kuala Lumpur and Singapore, they were in no position to help.

I am blessed that though we are not rich, we were able to pay for whatever needed to make her comfortable. We equipped her bedroom like a hospital room, with everything a hospital has. Similarly we bought all the medical supplies she needed.

I am blessed to have a maid, whose main task was to make sure that mother was clean and dry all the time. Though Mother became but a bag of bones, she was still very heavy as it was dead weight. To reciprocate, I have been cooking for my maid!

FEARS

Fear no. 1: I used to be scared that I might predecease Mother as Mother would not be able to adjust to life in some unfamiliar environment. Mother was actually very fit until the last 18 months. Her heart was strong and her blood count was good. She did not even get coughs and colds. I used to worry about it. Then coming to think of it, it would not have been my problem if that actually happened.

Fear no. 2: My current fear is that I might suffer the same fate and become an AD patient myself. Since my children have settled overseas, I would then end up in some nursing home.

ADVICE

I learnt that I needed to be well in order to be a good care-giver. I learnt that I needed to leave my home for a couple of hours daily in order to recharge my batteries, and to keep my sanity, especially in the early days when Mother was mobile and difficult. I have learnt that I must keep my mind occupied. Thus my active involvement in many non-government organizations.

(2,157 words)