

Caring for people with dementia: From a carer's perspective

by Mrs Kao May Wan Gwen

Alzheimer's disease was discovered a long long time. It is a disease that moves slowly and might start quite early in life and show no symptoms. When life expectancy went only into the 50's and 60's, symptoms were only just beginning to show before death--some forgetfulness. The full symptoms of dementia do not show until the 70's and beyond. Today people live to 90's and beyond. That is why we now see more and more elderly seniors with Alzheimer's.

It is difficult to describe the range of emotions a caregiver might feel or experience in a single day. Imagine being happy and then sad, caring then angry, focused then frustrated -- an almost endless stream of feelings and emotions that conflict.....

The caregiver lives an anxiety filled life day-after-day.

Imagine a person you know all or most of your life and their behavior changes--suddenly--and for the worse.

This person, your loved one, begins to act out behaviors that you never saw or experienced before. In the early stage of Alzheimer's caregiving, meanness and nonsensical behaviors are hard to accept.

In the beginning you want to scream. This might be your reaction when a person is intentionally mean to you. You come to the realization with a person suffering from Alzheimer's that this kind of reaction only makes things worse -- much worse.

If you have never cared for a small child from birth, you will have a harder time caring for a person with dementia.

There are many similarities between child rearing and for care of an Alz patient, but there are differences too. The main difference is that one is an adult with all the experiences of adulthood -- which may be somewhat forgotten - and the other is that a child is a blank page waiting to learn and to absorb experiences like a piece of blotting paper.

If you treat an Alz patient like a child, he is aware of it and may well be annoyed and become obstinate as a result. You tend to order a child to do a task, but you request an adult to do the same task. As a care-giver it is hard not to fall into the habits of child rearing.

When there is a child in the home, you need to child proof the environment. As the child grows old, this becomes less necessary. For an Alz patient it goes in the reverse direction. From a cluttered home situation in the early stage of dementia, it becomes necessary to be very neat and tidy with most things out of sight as the disease progresses to middle stage.

Some Alz patients in the middle stage like to pick up items and put it elsewhere. Prof Kao likes to put things in his trouser pockets or under his pillow. Which is a good routine - I know where to look for loss items. But this may not always be the case. It is better to put things out of sight. Fortunately he does not open cupboards and drawers. But every patient is different and you may have one that will open cupboards etc. You would need to resort to locks and bolts then!

The road travelled by a care-giver is a long and winding road. It begins on level ground. The more the care-giver can smooth the path, the easier it is to walk. How to keep it level? Make sure the patient stays as healthy as possible – good diet, plenty of exercise and brain stimulation. Some drugs will help too. Care-givers may need training to accomplish this result.

Maybe the patient will meet some other old age terminal illness before this road begins to climb.

Sooner or later, sadly, the road gets steep. The stress on the care-giver gets more as a result. At this time the care-giver will need more help and facilities to give him/her some time off from the constant stress.

Many in the public cannot see this road, cannot recognize this road. They have never had to walk it with an Alzheimer's patient and do not understand the landmines strewn along its path. They must understand this road as maybe sooner or later, with increasing longevity of life, they will find themselves treading its path with or without another person to help them along the way.

The statistics are known. 1 in 10 over 65 years old has symptoms of Alz. 1 in 3 has Alz over 80 years old.