



When I first told my friends that I was planning to do a graphic novel on dementia, some exclaimed, "Oh, dementia is like short-term memory loss, right?" Others said, "Why do you want to do such a depressing story?"

But for me, it is about breaking down the stigma of dementia.

It is about giving readers a better understanding of persons with dementia and of their caregivers.

A L L H A I N S

JAMES TAN



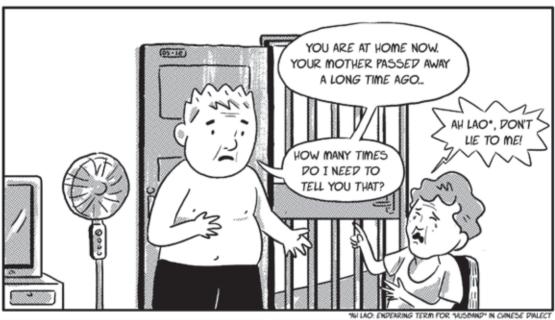
MY WIFE

My mother-in-law has had dementia for over a decade. Every week, when my wife and I visit her, I can see the complex relationship my father-in-law has with his wife.



















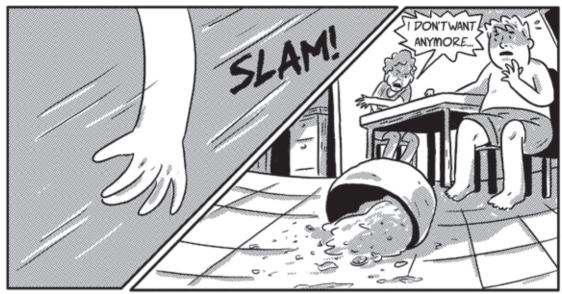


SUNDOWNING IS A SYMPTOM OF ALZHEIMER'S DISEASE AND OTHER FORMS OF DEMENTIA. IT'S ALSO KNOWN AS LATE-DAY CONFUSION. THE PATIENT'S CONFUSION AND AGITATION MAY WORSEN IN THE LATE AFTERNOON AND EVENING.









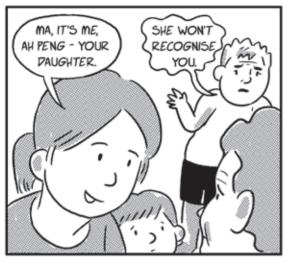








AGITATION OFTEN INCREASES IN THE MIDDLE STAGES OF DEMENTIA, PERSONS WITH DEMENTIA BECOME SUSPICIOUS OR EASILY AGITATER IT'S IMPORTANT FOR THE CAREGIVERS TO REMEMBER THAT THE DISEASE IS AFFECTING THE WAY PERSONS WITH DEMENTIA PERCEIVE THINGS.





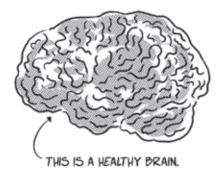


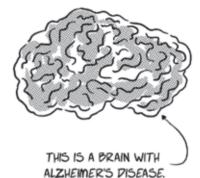


PEMENTIA IS AN ILLNESS WHICH AFFECTS THE BRAIN, CAUSING THE BRAIN CELLS TO DEGENERATE AT A FASTER RATE THAN NORMAL.

IT IS NOT NORMAL AGEING AS A RESULT, THE MENTAL ABILITIES OF THE PERSON WITH DEMENTIA DECLINE. THIS LEADS TO FAILING MEMORY, DETERIORATION OF INTELLECTUAL FUNCTIONS AND PERSONALITY CHANGES.

ALZHEIMER'S DISEASE IS THE MOST COMMON TYPE OF DEMENTIA.









THE PAMAGE TO THE BRAIN CELLS INTERFERES WITH THEIR FUNCTIONS AND ABILITY TO COMMUNICATE WITH EACH OTHER.

WHEN BRAIN CELLS CANNOT COMMUNICATE NORMALLY, THINKING, BEHAVIOUR AND FEELINGS CAN BE AFFECTED.





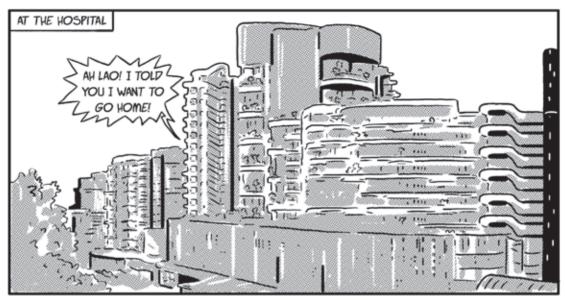


































"I WANT TO GO HOME" IS USUALLY A REQUEST FOR COMFORT RATHER THAN ASKING TO GO SOMEWHERE. WHEN RESPONDING THE GOAL IS TO REPUCE THE PERSONS ANXIETY AND FEAR.





"CAREGIVERS CAN TAKE HEART THAT AT TIMES WHEN THE PERSON ACTS UPIT'S THE DISEASE SPEAKING AND NOT THE PERSON.
PERSONS WITH DEMENTIA HAVE TIMES WHEN THEY ARE LUCID AND CAN RESPOND APPROPRIATELY. WHEN THAT HAPPENS, IT MAY
FEEL AS IF THAT THE PERSON HAS BEEN FAKING IT AT OTHER TIMES, BUT THEY'RE JUST HAVING ONE OF THEIR GOOD

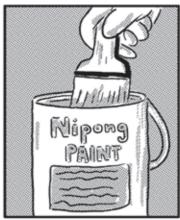




































































VIE: SISTER IN CHINESE PIALECT















Man of the House

Nicholas Tse, 44

Nicholas Tse's father was diagnosed with Alzheimer's disease in 2001, after a bout of panicked confusion over whether he had gone to work after waking up from a nap. The Tse family's journey with Alzheimer's disease was a long one lasting 17 years. Nicholas's mother is now also showing signs of dementia.

Tell us a little about your father.

When my siblings and I were growing up, my father was very much involved in his garment-manufacturing business. I remember accompanying him on trips to his factory in Eunos and making delivery runs to the various retail outlets – he was often busy and focused on making ends meet. But with his family he was very obliging. He doted on us and went out of his way to give us whatever we wanted.

When your father was first diagnosed with Alzheimer's disease, how did it impact your life?

My siblings and I were in our 20s when he was first diagnosed, so we were all busy working, and initially we were quite detached when it came to looking after him. It was mostly my mother and our domestic helper who looked after my father. I think I was more worried about the impact on my mother's health, because she had suffered from a brain tumour when she was younger. Alzheimer's disease was a huge disruptor for us, especially when we were in the prime of our lives, and I was resentful.

So what did you do when spending time with him?

My father didn't have many pastimes outside of his business. But he did like music. His favourite songs were by Teresa Teng. And he knew some hymns and Christian songs after he started going to church. So I would play these tunes for him. He would usually whistle to the music. I think it calmed him. Initially he watched some TV, but later on, he seemed less interested.

How did the disease affect him throughout the 17 years? I am sure there were difficult times.

His mood swings could be quite emotionally sapping. He would sometimes get very angry or frustrated, which was manifested through his hitting a wall or his own head and lamenting that he wanted to die. This was when it became very difficult for those around him. We would try to comfort him, tell him to calm down and that it was okay. Sometimes it helped. Sometimes we just let him be. It would have been worse to have a confrontation with him during an outburst.

Once he was lost for more than a day because he did not get off the bus together with my mother. We had to make a police report, and we traced the bus route that went all the way to Jurong. In the end we found him at Tiong Bahru!

From 2009 to 2015, my father went to a day care centre. In the last two to three years of his life, he would lie in bed more frequently and needed more support walking. By 2017, we had to use the wheelchair to move him around. He also had to use diapers, which he used to take off, but he stopped doing that later on. So it became quite difficult for my mum and the one helper, who was physically not that strong, to take care of him. We had to engage a second helper to help take care of my dad full time. This was about three years ago after he stopped going to the day care centre.

Just last year, there were moments when my dad was in hospital that I found his eyes showing an occasional alertness. It made me wonder if he was still cognitively present. When I spoke to him and looked closely enough, I saw his eyes sometimes seemed moist and he seemed to understand what I was saying. But you will never really know.

Did your own attitude towards caring for your father change throughout the 17 years?

I did not think about it too much when I was younger. When I was younger, my response was to escape, but as I got older, I felt I had to step up. I knew I still had to be a son to my father.

I tried to spend time by involving him in my life. For example, if I had an upcoming tournament at work, I would bring him downstairs to play basketball; I would sometimes practise my Frisbee throws with him to improve my weekend games; or if the car needed a wash, I would take him to wash the car with me. When I was a kid, he was always busy, so I realized this was like a second chance to spend time with him.

When did you suspect your mother might have dementia? And what is your plan now for her?

It started when she showed a general confusion and said things that were out of sync with reality. For example, she would say there was nothing wrong with my dad even though he clearly could not do anything by himself. She also thought my grandfather was still alive. We have been playing Scrabble with her every day – five to six games a day, to help keep her mind active.

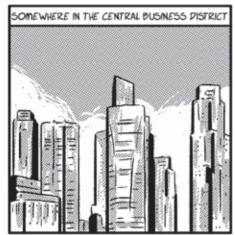
Do you have any advice for someone looking after a person with dementia?

Don't take what they say too seriously, especially when they say things that may be hurtful and don't make sense. At times, learning to go along with their mistakes may be the kinder thing to do, because pointing out their mistakes can make them feel bad and confused.

Caregiving is often unappreciated. Sometimes you walk the journey alone, but you must speak up when the going gets tough, so that others around can look out for you too.

MY MOTHER

This story came about after I interviewed my friend who has been taking care of her mother who has dementia. It is a challenging period for her, having to deal with her mother's unpredictable moods.

















"WITH NORMAL AGEING THE ELPERLY MAY BECOME FORGETFUL AND THERE ARE MANY CAUSES FOR POOR MEMORY. FORGETFULNESS PER SE POES NOT EQUATE WITH PEMENTIA.



















































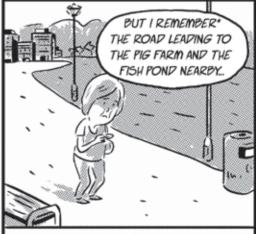












*PERSONS WITH PEMENTIA MAY HAVE IMPAIRMENTS IN SHORT-TERM MEMORY BUT REMOTE MEMORY CAN BE LEFT RELATIVELY INTACT. THEY'RE ABLE TO REMEMBER PUBLIC AND PERSONAL EVENTS MANY DECADES AGO.







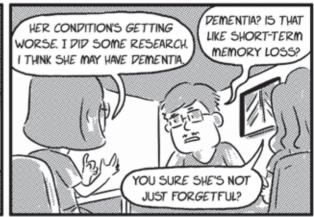


MY MOTHER SOMEHOW MANAGED TO REMEMBER MY PHONE NUMBER CORRECTLY.

> I HAP TO RUSH POWN FROM WORK (AGAIN!) TO BRING HER HOME.













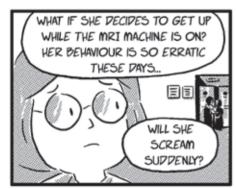








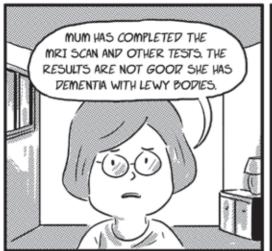




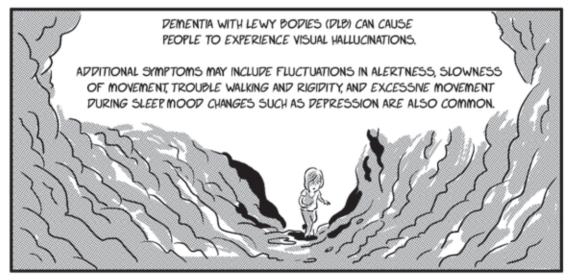




ME THAT FOR SOME REASON IT FELT THERAPEUTIC TO BE INSIDE THE MRI MACHINE.























I DECIDED TO LEAVE MUM AT MY SISTER'S PLACE DURING THE DAY WHILE I WAS AT WORK.





















I HAD BOUGHT BAGS OF MARBLES AND PILL BOXES. I LIED TO MUM THAT A FACTORY HAD HIRED US TO PACK THESE MARBLES IN THE PILL BOXES.

AT THE END OF EACH DAY, MY SISTER AND NIECE UNPACKED THEM - FOR MUM TO PACK THE NEXT DAY.

THIS KEPT HER OCCUPIED FOR A WHILE UNTIL ONE DAY...

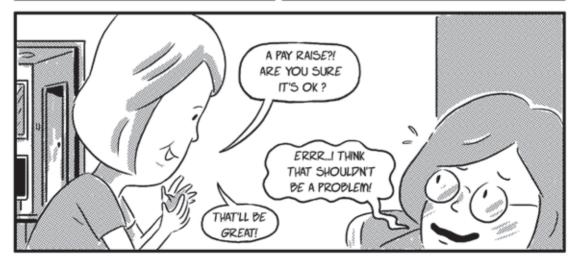








































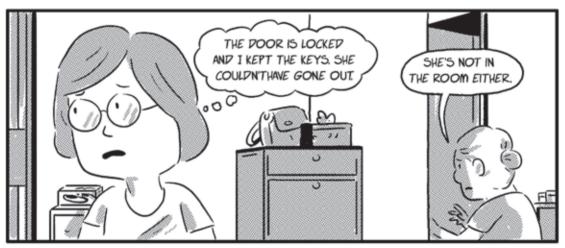










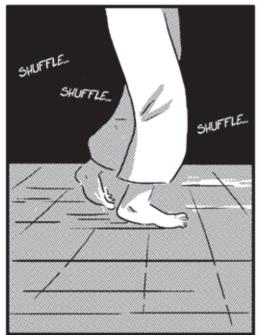
















PERSONS WITH PEMENTIA CAN GET EASILY CONFUSED WITH THE TIME OF DAY, THEY MAY START WANDERING ABOUT IN THE MIDDLE OF THE NIGHT, BECAUSE THEY THINK THEY HAVE TO BE SOMEWHERE AND PON'T UNDERSTAND THAT THEY'RE SUPPOSED TO BE SLEEPING















MY MUM'S PEMENTIA GOT PROGRESSIVELY WORSE. MOST OF THE TIME, SHE'S IN HER OWN WORLP, CREATING HER OWN STORIES AND REENACTING HER OLD MEMORIES. BUT I WILL JUST FOLLOW ALONG AND SEE WHERE IT LEADS...WITH A SENSE OF HUMOUR AND LOVE.



Becoming a Kid Again

— Steven & Judy Tan, 68 —

Judy and Steven Tan are retirees. They had been caring for Steven's mother for some 20 years until she passed away in her 90s. She was never officially diagnosed with dementia, but was exhibiting the symptoms all through those years. The Tans describe caring for their mother like caring for a baby or a child.

Tell us a little about Grandma Tan.

Steven: When we were young, we hardly saw our parents. Being performers in a wayang¹ troupe, my parents moved around a lot, performing in Malaysia and Singapore. Most of the time we lived with a nanny in the kampung². My parents would visit us in the kampung for a few hours each time, or at most, a few days. They didn't really have a pastime or a hobby. I think my mother enjoyed cooking for us. After she retired, we would gather every weekend at my youngest brother's house and she would cook for us.

When did you start to suspect that Grandma Tan had dementia?

Steven: I think the earliest sign was when she claimed her daughter-in-law was stealing her things. She offered her clothes to my wife instead, and said she wanted to give them to my wife because my youngest brother's wife was stealing her clothes.

Judy: I asked her why she would want to steal her clothes. I could recognise the signs because my own mother also had dementia. My mother was very fierce and every night, she would stay up waiting for my sister to come home and accuse my sister of stealing her alcohol. For Grandma, I think her dementia started to show when she stopped cooking every Sunday for us. When you are old, you must keep active.

Steven: Sometimes I feel that if she had kept cooking every Sunday for us, she may not have got dementia so fast. She would have needed to go to the market and think about what to cook.

Did you consult a doctor about her symptoms?

Steven: She saw a doctor regularly for her kidney disease, but not for dementia. There was very little public information about dementia 20 years ago. We learnt about it from speaking with friends. And we just thought that once you grow old, you would naturally get some form of dementia.

How did her dementia develop all through the 20 years? Was it difficult for you to cope for so long?

Judy: Soon after she showed early signs of dementia, she came to live with us. In the beginning we would play videos of Teochew opera for her, and she would

sing along. Later on, she would doze off while watching. She would also offer to help me peel onions. But she would not really know how to do it.

Steven: Actually her dementia worsened quite fast. Soon after she accused my sister-in-law of stealing her clothes, even though she could still speak, she spoke less and less, and lost interest in most things. And at some stage, you would not understand what she said. The first 10 years she could still walk, and once, she walked alone to the park nearby and urinated there. At one stage, she liked to squeeze her own arms, and there would be bruises. And in the last year of her life she could no longer swallow well, and she ate very little. I think we were very lucky that my mother was quite easy to manage when she had dementia.

Judy: We also had a maid to help. And we kept to a daily schedule and system. She would wake up at 12pm, take her lunch, rest, and then at 3pm, it was her teatime, and she would rest until dinner. She was quite calm and kept to herself. If she did not want to eat, she would just refuse to open her mouth. At first she did not want to wear her diapers, but after a while, she also accepted it. Even if she woke up in the middle of the night, she would just lie in bed. She would be resting most of the time and was really quite peaceful. But I know every dementia case is different. Some will have challenging behaviours or be very difficult to look after.

Did you feel differently towards her after she had dementia? Were there happy moments?

Judy: We saw her as a child and treated her like one. We would touch and stroke her face. I felt she knew that we were her children.

Steven: At times she would cry, but all she wanted was some attention. We just touched her head affectionately, smiled at her and talked to her. She was like a kid. Once we gave her a soft toy, a doll, and she kept holding it. She had it for a long time. When we talked to her, we would ask, "Have you eaten?" and sometimes she would smile back or say something incomprehensible. I felt that as long as she was okay, we were happy. Maybe the happier moments were when we celebrated her birthdays in her 80s.

Do you have any advice for those looking after someone with dementia?

Steven: Make sure they don't fall. Falls will lead to many issues for an older person. It is also good to have a routine and schedule.

Judy: Taking care of persons with dementia requires a lot of patience, and you will need to understand and adjust to their new character and personality.

¹Chinese street opera

² Small village or community of houses

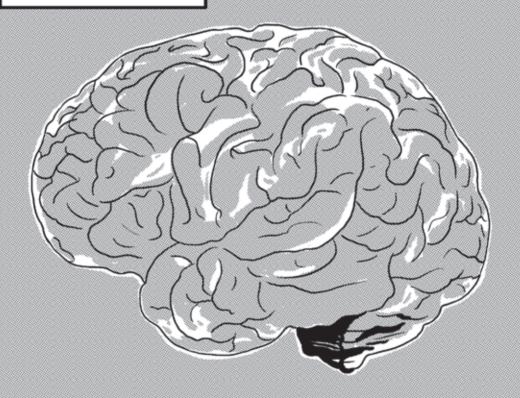
MYSELF

I try to put myself in the shoes of a person with dementia and imagine how it would be like.

THE BRAIN IS THE MOST COMPLEX ORGAN IN THE BODY.

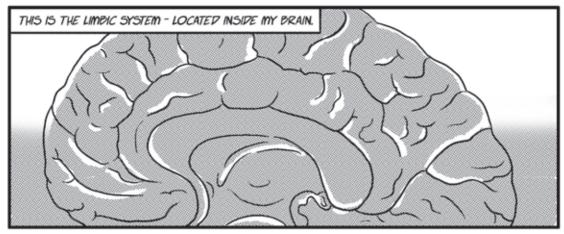
IT IS MADE UP OF AN INTRICATE NETWORK OF BILLIONS OF NERVE CELLS CALLED NEURONS.

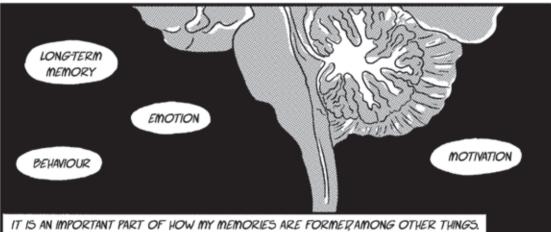
THE AVERAGE ADULT BRAIN WEIGHS BETWEEN 1.3 KG AND 1:1 KG



HOW ARE OUR MEMORIES STORED IN IT?

DO OUR IDENTITY AND SOUL RESIDE IN THE BRAIN?









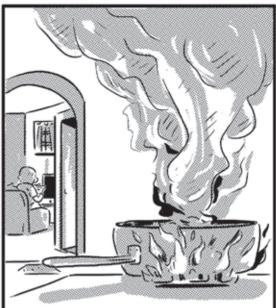






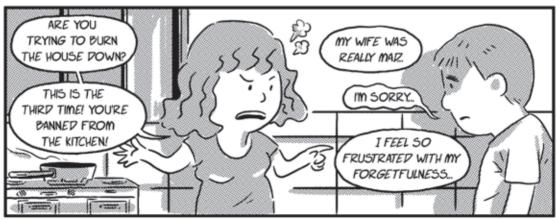
























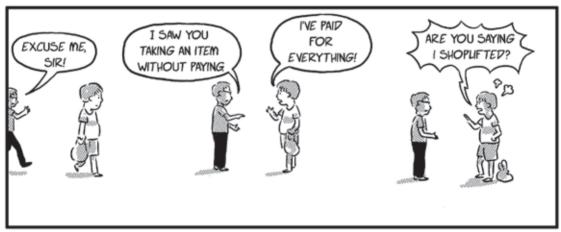




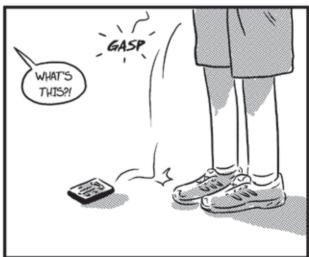




















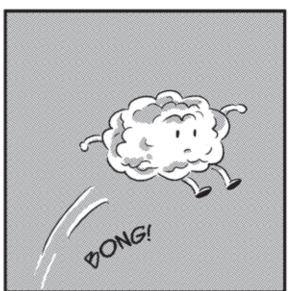


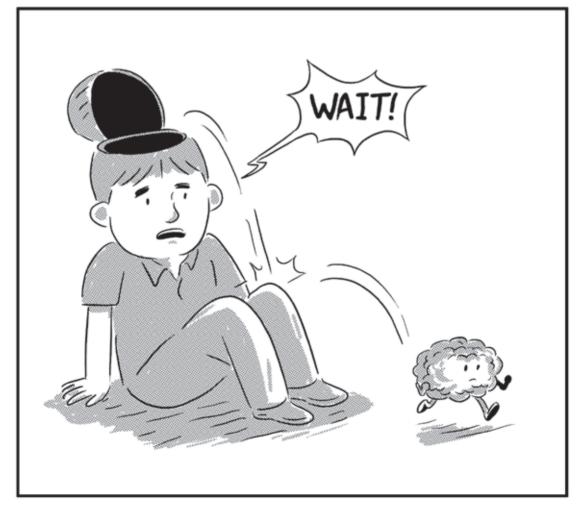






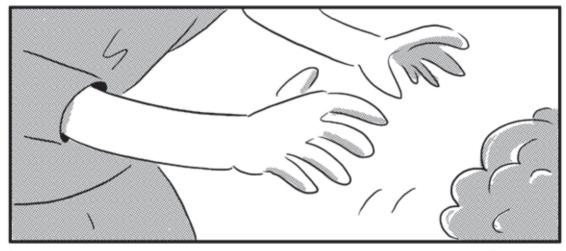
















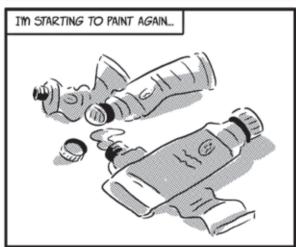


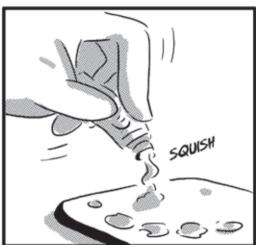


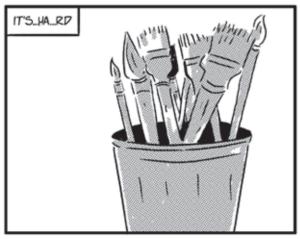


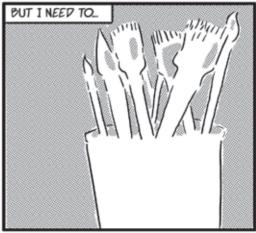




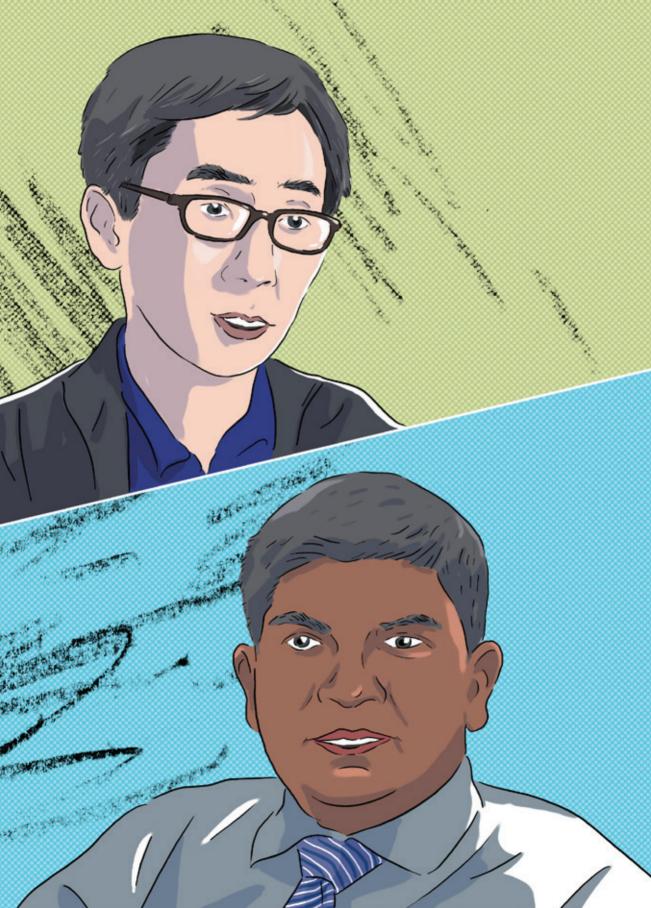












Understanding Dementia

— Dr Nagaendran Kandiah & Dr Philip Yap —

Dr Nagaendran Kandiah is a senior consultant with the National Neuroscience Institute at Tan Tock Seng Hospital. He specialises in Alzheimer's disease, dementia and cognitive neurology. Dr Philip Yap of Khoo Teck Puat Hospital is Director of the hospital's Geriatric Centre. He has a keen interest in both the biomedical and social aspects of ageing, including dementia and palliative care.

What is dementia? What are the initial signs that one should watch out for?

Dr Nagaendran: Dementia is an umbrella term for the group of symptoms that is related to cognition. Many diseases of the brain can cause dementia. In terms of brain diseases, there are about eight to nine diseases that can contribute to dementia. The most common is Alzheimer's disease, followed by vascular disease.

There are mild, moderate and severe stages. And the set of issues is different for each stage. For the mild stage, it may be a problem with memory, while in the severe stage, persons may exhibit behaviour changes or experience hallucinations.

If you have memory loss that is occasional, I will not be too worried about it. A person who is busy, who is involved in multiple things, who is not having enough sleep, who is stressed, can be forgetful occasionally. But if these types of problems keep recurring, don't go away and become obvious to people around you, and if they are persistent for more than six months, then you should definitely seek an assessment to find out if you are suffering from dementia.

It is part of the ageing process that you have difficulty with your thinking process. But the difficulty is mainly a slow processing speed. So take something you could do easily when you were in your 30s: now you take two or three times longer. If you are still able to complete the task, that is normal ageing. If you cannot complete the task, then it is more worrisome.

Can young people suffer from dementia?

Dr Nagaendran: By definition, anyone who is under 65 years who has symptoms of dementia can be considered to have young-onset dementia. In Singapore, our statistics shows that the number of patients with young-onset dementia is steadily increasing. This could be related to increasing awareness among younger people. Other factors include lifestyle; medical history of stroke, heart disease, diabetes or high cholesterol; or a family history of dementia.

We also do not know the exact reasons why some people start to have Alzheimer's disease, especially younger people. 25–30% of these cases are genetically related. They have a certain gene in their system that increases the deposition of a protein called amyloid, and this is what causes the loss of brain cells, a typical hallmark of Alzheimer's disease.

Do you have any advice on managing one's risk of developing dementia?

Dr Nagaendran: Social interaction is found to be very useful. People who are not socially active are at a higher risk of developing dementia. In terms of brain disease, every day counts. Unlike other parts of the body, once you have lost a brain cell, it will not come back. So if you want to delay or maximise someone's brain potential, the person needs to be diagnosed early.

Is there now more awareness of dementia and hence earlier diagnosis and greater acceptance?

Dr Philip: 10 to 15 years ago, we used to see just a small proportion, probably 20% of our patients, with early dementia. The rest will be patients with moderate or even late-stage dementia. Today, we see perhaps 50% of our patients who present memory complaints to our clinic and who show very early symptoms.

But there is still a tendency for people to not want to be associated with dementia. There is still a stigma associated with dementia. But with so many more people who are diagnosed with dementia, there is perhaps a need to normalise it. This is not to say that dementia is normal, but there is a need to help people to recognise, accept and say that it is a form of cognitive handicap. It is not unlike someone with a physical handicap. They can still try to continue to live life as normally as possible, with the necessary help.

What is a common misperception of people with dementia? Do you have any advice for how we can relate to them?

Dr Philip: There is a tendency for us to sometimes not pay attention to people with dementia, and to what they have to say. Because we think that they have dementia, we think that what they say is not of value. This is not true. People with dementia, especially in early-stage or even moderate-stage dementia, can still make choices for themselves and they can still have their own preferences. Their opinions are still to be valued and that's very important.

TIPS FOR CARING FOR SOMEONE WITH DEMENTIA

1. Communication

Losing the ability to communicate can be one of the most frustrating and difficult problems for persons with dementia, their families and carers.

As the condition progresses, persons with dementia experience a gradual lessening of their ability to communicate.

They find it more and more difficult to express themselves clearly and to understand what others say.

When cognitive abilities such as the ability to reason and think logically deteriorate, the person with dementia is likely to communicate at a feeling level.



a. Keep sentences short and simple, focusing on one idea at a time.



c. Don't argue. It will only make the situation worse.



b. It can be helpful to use orienting names whenever you can, such as "Your son Jack".



d. Don't tell them what they can't do. Instead suggest what the person can do.

2. Loss of appetite

Forgetting how to chew and swallow, ill-fitting dentures, insufficient physical activity and being embarrassed by difficulties can all result in a loss of appetite.

3. Overeating or insatiable appetite

Loss of memory and problems with judgement can cause difficulties in relation to eating and nutrition for many persons with dementia.



a. Try to make mealtimes simple, relaxing and calm. Be sure to allow enough time for a meal (assisting a very impaired person can take up to an hour or more).



a. Have five to six small meals each day.



b. Encourage physical exercise.



b. Have low-calorie snacks available, such as apples and carrots.

4. Dressing/Forgetting how to dress

Persons with dementia may not remember whether they are getting dressed or undressed. In addition, they may forget to change their clothes, put them on in the wrong order or put on many layers of clothes. They may realise they have an item of clothing but have no idea which part of the body it goes on.

5. Lack of privacy

Getting dressed is a very personal and private activity for most of us. Having to get dressed or undressed in front of another person can be an uncomfortable experience. When a person requires assistance in self-care activity, it symbolises a loss of independence, which can be very difficult to accept.



a. For some people, buttons, snaps, hooks, zippers and belt buckles are too difficult to manage. Use sewn-on Velcro on clothing as they are easier to manage than buttons, hooks and zippers.



a. Let the person manage most of the daily tasks as much as he or she is able to. Intervene to help only when necessary.



b. Simplify the number of choices. For example, offer just two outfits to choose from.



b. Close the door and pull down the blinds to create a feeling of privacy.

6. Sleeping

Problems with sleeping are a common occurrence for persons with dementia. Some people sleep during the day and are awake and restless at night. Some are no longer able to tell the difference between day and night, while others are simply not as active as they used to be and consequently need less sleep.

7. Going out

Informing someone of a planned schedule may be best for many people. However, this may not be so for persons with dementia as they may be overwhelmed by the information.



a. Not recognising self or others in a bedroom mirror may cause confusion. Removing or covering the mirror may be helpful.



a. Telling persons with dementia the appointment time may make them want to leave immediately or repeatedly ask, "When are we going?" Hence, it may be best to only tell them just before you prepare them for the outing.



b. Night lights help cut down on confusion and may assist them to find the bathroom.



b. When you do tell them, be prepared to leave within the next few hours.



Acknowledgements

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SUGGESTED ACTIVITIES FOR PERSONS WITH DEMENTIA



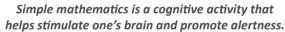




Memory games help to improve concentration and the ability in finding similarities and differences in objects.



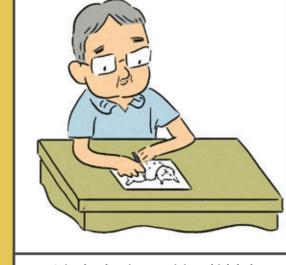






Dancing to music can trigger fond memories and emotions, and it's a social activity which increases strength and flexibility, and helps to reduce stress.





Join-the-dots is an activity which helps to maintain the skill of sequencing.











Sing-along sessions help persons with dementia utilise their visual and auditory senses, while also lengthening their attention and retention span.







Jigsaw puzzles help with better problem-solving skills and improve visual-spatial reasoning.



AN HOUR LATER

I'M HUNG I NEED TO MY LUN

I'M LIKE A JUG..

WHAT'S THIS 2. WHY IS

ECCI MY MEMORICS



