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VOICES

We feature diverse perspectives — part professional advice, part heart felt voices — on what it means to care for a person with dementia. When the going gets tough for the carer, we can always tap on the collective wisdom of others to find support and learn from each other. We hope to inspire caregivers to soldier on together as a community.

There is no fixed template for caring

RUTH WONG, ALZHEIMER'S DISEASE ASSOCIATION (ADA)

Could you describe the work that you do with families caring for a person with dementia?

I run a project for the Alzheimer's Disease Association (ADA) called “Memories Café.” Every Saturday, we would invite persons with dementia and their families to come and interact in cafes operated by our partners. We adopted this idea from the Netherlands where it was called “Alzheimer's Café.” For the first hour, the persons with dementia would collaborate with artists in live performances — singing, dancing, drumming and the like. For the second hour, they would engage in an activity that suits them. They may simply be chilling out or enjoying themselves.

I also run a programme called “Voices for Hope” that empowers caregivers and persons with dementia to be self-advocates. It is an 8- to 10-week programme where they explain what it means to care for persons with dementia on different community platforms. I'm currently on my fourth cohort of participants. Last November, we led the first cohort on a study trip to Taiwan to meet their counterparts there.

How did you come to do this work related to dementia?

My background is actually in early childhood education. I also lived with my grandmother for 9 years and became curious about ageing — how people get old and how to live well in old age. I later took a part-time degree course in Gerontology and eventually completed the degree in Canada where I did an internship in a dementia-care setting. I somehow grew to like working with persons with dementia and my supervisors there were also supportive. After returning to Singapore, I worked with the Tsao Foundation on elder-related programmes before running “Memories Café” for the ADA.

What did you learn in the process of doing this work?

It really shook my concept of ageing. We often stigmatise this process and assume that growing old means becoming useless or helpless. Actually, you can age very successfully and enjoy growing old.

Dementia differs from general ageing in that it involves memory loss. Just because persons with dementia have lost their memory does not mean that they have lost everything. They retain many abilities that they can still contribute and can live very well if their condition is properly managed. They can still respond with humour. They can still be a grandma, a parent, a good spouse, and love their family.

I am struck by their positivity. Of course some of them may be negative but it's just a phase — if they can acknowledge the condition and walk through that, they can live very well. Persons with dementia can maintain their independence, make decisions and express themselves like anyone of us. That humanity, to me, is very special.

> ***“Persons with dementia can maintain their independence, make decisions and express themselves like anyone of us. ”***

For families who are new to caring for a loved one with dementia, what should they pay attention to?

Every family is different and there is no set way to care for a person with dementia. It depends on the relationship and who the primary caregiver is. If it's a spouse, for example, the care would come about differently from that given by adult children. The common theme is the love that they have for each other. Caregivers sometimes acknowledge that their role now is to care — with commitment, perseverance and a sense of purpose.

People often assume that caring for a person with dementia is burdensome but caregivers sometimes reply otherwise. They say, “I also received a lot from them. I learned new things, like how to respond creatively to unexpected behavior.” For them, caregiving is an experience of learning and growing together. When a caregiver says that it means that they are enlightened — they have walked through it and see caregiving as a journey.

Are there any misconceptions around caregiving?

Many people talk about caregiving (i.e. “I give care” or “I care *for* you”) in a way that reinforces the disability of

“They can still be a grandma, a parent, a good spouse, and love their family.”

the person being cared for. However, the persons with dementia still want to exercise their autonomy. They do not like to burden people and still desire the dignity of doing things on their own.

We should re-focus towards the concept of a care partner (i.e. “I partner with you for your care”) where I come in on your invitation and we share power in a co-created caring situation. This can work regardless whether the primary caregiver is the spouse or adult children. It should be about empowering persons with dementia to live the way that they want to.

What differentiates the families that cope better with the caregiving process?

The first thing is to accept that dementia has come into the family. Both the caregiver and the person with dementia have to acknowledge this. If you do not do so, it becomes a constant fight and this makes caregiving very difficult. The caregiver should also accept that this person now lives with dementia and their relationship with the care recipient will transform.

Some families take a long time to accept while others do so quickly and life carries on. Because each family’s dynamics are different, the care will show up differently in different families. With that in mind, each family’s decision on how best to care for their loved one needs to be respected. It’s not about good or bad but which phase of the caring journey — and which phase of dementia — they are in.

You mentioned that persons with dementia can still live very well if their conditions are properly managed. What are some ways to manage and intervene?

One, routine is very important. You can set up a routine for their daily activities — especially for persons with early stage dementia. Even ordinary people’s lives revolve around rituals like breakfast and lunch. This helps to explain why persons with dementia cope really well with day-care — because it offers a specific routine.

If the person with dementia is “free-flowing” and dislikes routines, it then becomes a question of how you meet their needs with sensitivity. Do you totally take over, guide step-by-step, or just gently coax the care recipient to do something? There is no fixed template and each caregiver does it differently.

One aspect to intervening well is to maintain a sense of readiness and match the pace of the person with dementia. For example, you can establish eye contact, call them by their name, and then gradually ease into a conversation or request. Of course, one must know the person first and it depends on their stage of dementia. Sometimes you may need to slow your speech and wait for a cue of readiness.

There is no fixed template to caring and each caregiver does it differently. It really depends on the relationship or even how one is feeling at a given moment. Nevertheless, it should always be about providing care in a respectful way. For persons with dementia, their emotion is the last thing to go so it’s about how caregivers make that emotional connection. If the person with dementia feels at ease, it is probably right.

Can persons with dementia do things for themselves?

Most definitely. For those in the early stage, they can do pretty much everything on their own. It becomes tougher for those in the moderate or advanced stage, depending on which part of the brain is affected. If the parts that determine mobility or continence are not affected, they can still perform certain tasks. I have seen moderate-stage persons with dementia do things independently.

“If the person with dementia feels at ease, it is probably right.”

You recently led some self-advocates on a study trip to Taiwan. What were some highlights from this trip?

This was a trip organised by ADA to bring six families caring for a person with dementia to Taiwan to meet their counterparts. The objective was to learn from the self-advocacy group in Taipei and also to let them have a good time — to prove that persons with dementia can enjoy travel like any one of us.

There were many beautiful moments during that trip. I was very moved by how persons with dementia look out for each other. For example, we were crossing the street on our way to the night market with two gentlemen — Steven and George. Steven is still in the early stage of dementia and George is very young — he’s only 48. Steven walks slowly due to a kneecap problem. Whenever George walks along the sidewalk, he would look back and ask, “Steven, are you ok?” and Steven would reply with humour, “You mean you want to carry me if I’m not ok?”

These persons with dementia use humour to express their familiarity and care for each other. They accept each person for who they are and cultivate close bonds. It is amazing to see how they call each other by their first names, recognise familiar faces, and feel this sense of belonging as a community. I think that makes it special for them.

Does a caregiver's mental state affect the quality of care given to the person with dementia?

If the caregiver is calm and at peace, you will notice that the person they care for is okay. There is a concept in early childhood education called "Transfer Anxiety" that probably applies here. If the mother is anxious, the baby will cry once she carries the baby. This is because young children are very sensitive to their parents' emotions, and so the anxiety transfers from mother to child.

Similarly, persons with dementia are sensitive to their caregivers' emotions. If you are tense, they sense it from your body language and start to feel anxious. This is because you are now the most important person in their life. It really helps if caregivers are aware of their own emotions. They should take a break first if they think that now is not the right time to approach the care recipient. In that way, they do not "transfer" their anxiety to the care recipient.

Why should caregivers look after their own needs?

As a caregiver, whatever you do affects the person you are caring for — like a mother caring for her child. Therefore, it always works very well when caregivers are aware of their own limits and can say, "No, I need my self-care first." You have to feel ready to give care. This only happens when you are calm and not exhausted. It helps for carers to have this awareness.

You can tell that the person with dementia knows. They will learn to wait if the caregiver finds a way to communicate with them. Of course you may have to pace it. There may be times when you have to set aside your momentary needs to serve the care recipient first. You just need to be aware of what will work best. It will always be a trade-off and a balance.

We advise caregivers to always set aside time for themselves and not be the only person caring for their loved ones. Let go and let others come in to care. That "me-time" is important. Caregivers find it hard to let go because they see it as their responsibility. They fear that they are troubling someone or something unforeseen might happen. Those are the carer's stress.

I feel that they need to trust the person with dementia — that they are adults and have lived their lives for many years. They know and can tell us if they need anything.

"If you are tense, they sense it from your body language and start to feel anxious. This is because you are now the most important person in their life."

What is your dream invention to make life easier for caregivers or persons with dementia?

A robot that knows everything about the person with dementia — his or her needs, wants, hopes, and even memories. That makes it so much easier for the caregiver. Persons with dementia have brains that are deteriorating. There may come a point when they can no longer express themselves or even recognise you. It becomes tough to anticipate needs unless the caregiver knows this person intimately and thoroughly.

With the onset of dementia, the loss of memory and life experience is very painful because this makes us unique and gives us our identity. The memory of our lived experiences coloured with emotions makes us special. This is why persons with dementia get very scared of losing their memory, especially in the early stages when they are still aware. This is a type of fear that can make you feel helpless, like being a kid that does not know how to find his way outside.

Imagine if this robot can store these memories and put it into the brain of the person with dementia — how nice would that be?

"You can age very successfully and enjoy growing old. "

"There is no template, so just grow with it because that's all you can do."

Do you have any final advice for families embarking on this caregiving journey?

Just be yourself. Be who you are and do what you can. Knowing who you are is important. As the journey progresses, you will learn and your abilities will grow, and there will be more tricks in your bag that you can use. There is no template, so just grow with it because that's all you can do. Don't forget to love yourself.

▶ Visit www.alz.org.sg to find out more about the various support services of ADA.

Ruth's Recommendations

1. There is no correct or fixed template to care for a person with dementia. It is different for every person, relationship and family.
2. Having a routine is important. Organise the day around mealtimes and activities.
3. Match the pace of the care recipient. Make eye contact, call them by their name and ease them into a conversation.

Caring for someone with dementia isn't easy

Living with a person with dementia exerts a huge toll. It requires immense patience, time and understanding. Do not feel guilty for taking time off whenever you need a break. Go easy on yourself.

ME-TIME MAKES FOR BETTER WE-TIME

Be kind to yourself.
Allow yourself regular breaks while taking care of your loved ones. Go for a walk in the park, indulge in self-care rituals, or simply steal a nap when you're tired.
KIVIK chaise lounge From IKEA

If you don’t use it, you’ll lose it.

DR WONG CHEK HOOI,

SENIOR CONSULTANT, DEPARTMENT OF GERIATRIC MEDICINE, KHOO TECK PUAT HOSPITAL
DEPUTY EXECUTIVE DIRECTOR, GERIATRIC EDUCATION AND RESEARCH INSTITUTE

What happens when a person has dementia?

It depends on the severity of the dementia when it is diagnosed. Everyone knows that dementia relates to memory and forgetfulness, but we forget that it covers more than that. It also involves how they perceive spaces and the way things are arranged. This explains why persons with dementia can get confused and lost. It may even reach a point where they cannot do basic activities like putting on their clothes. Because dementia involves spatial perception and how people see things, I see a role for design of the physical environment to help persons with dementia cope with everyday living.

How does dementia differ from cognitive impairment?

Cognitive impairment is an all-encompassing term of which dementia is a subset. To give a non-dementia example, a person who is depressed may have problems processing memory, people or the environment. We can say that this person has cognitive impairment, but he may not have dementia. Cognitive impairment is a larger term than encompasses dementia — which is a specific, clinical diagnosis.

Are there different types of dementia?

Two main types of dementia form the majority of cases. The first is the Alzheimer’s type, which is mainly a degenerative process in the brain. The second is the vascular type, which is due to pre-existing conditions like high-blood pressure, diabetes and high cholesterol. Other types of dementia also exist but they are generally less common.

> *“I see a role for design of the physical environment to help persons with dementia cope with everyday living.”*

At what stage are dementia cases commonly diagnosed?

Most patients are unfortunately diagnosed at the late stage. This is because memory impairment or changes in environmental perception are mistakenly perceived as signs of normal ageing. We therefore end up diagnosing them at a later stage.

What should a family pay attention to when a loved one gets diagnosed with dementia?

Firstly, they should understand that this is memory impairment that is not normal with ageing. A normal ageing person has some impairment but it doesn’t affect how he or she functions. Dementia is very specific. It affects how the person functions — like the way they interact and cope with the environment. Family members need to identify it and seek help.

Secondly, we should establish the diagnosis. We seldom diagnose dementia quickly because cognitive impairment has many causes. This is important as cognitive impairment caused by something like depression can be reversed. However, dementia is irreversible and we know its progression once we give the diagnosis. They will get progressively forgetful, with all the problems associated with memory and their perception of the environment. This will affect how they function.

If dementia is irreversible, what are appropriate health and wellness goals for a person with dementia?

The progression of dementia can be slowed down. There are different interventions to slow progressive loss in memory and function. We encourage persons with dementia to stay physically active. There must also be mental stimulation — it could be crossword puzzles or sudoku. It goes back to the old saying, "If you do not use it, you will lose it."

It is important to slow down the progression of dementia so that the person can still have a very good, independent quality of life. Both physical and mental activity are good. Lifestyle changes also help — like not smoking, or adopting diet changes that prevent diabetes, high blood pressure or high cholesterol. These are things that people can do.

We sometimes give medication to prevent quick deterioration in the mental function of a person with dementia.

Does diet play a role in the health and well-being of persons with dementia?

The risk factors for vascular dementia — one of the 2 common types of dementia — are similar that for diabetes and hypertension. Foods that pre-dispose a person to these conditions also pre-dispose one to dementia. Therefore, it is good to avoid foods that are too sweet, fatty, or have high salt content.

> *"We encourage persons with dementia to stay physically active."*

There is some belief that green tea and other tea substances may help dementia. It's still under study but if you enjoy green tea, please continue to drink it. There are other things like gingko and vitamin E but the evidence for consuming more of it is not robust. I will still recommend foods that prevent diabetes, high blood pressure and cholesterol.

Does the physical environment affect persons with dementia?

Definitely. Whether it's indoors or outdoors, the environment can enable or disable someone from engaging in physical activity. Beyond just performing the activity, it is important for persons with dementia to participate in more engaged ways. An environment that is enabling allows a person with dementia to still go out to do their various activities. Design can help to overcome these disabling environments.

How does a familiar environment help a person with dementia?

Usually, for a person with early-stage dementia, home is the least confusing environment because of its familiarity. With ageing, we tend to not want to use too many of our brain cells. We are "cognitive misers" in that sense. In other words, we choose to do familiar things because it needs very little thinking, and is almost automatic.

For example, when you return home you'll likely place your watch and wallet in a particular place. If you forget to place these items in the same location, it becomes hard to find them. It's the same thing with dementia. They just have a lower threshold so it is harder for them if they are not familiar with it.

This does not mean that they cannot deal with new environments. The new environments need to enable them to move around and perceive things more easily. For example, in a room where everything is white — the walls, the furniture, carpets, etc — a person with dementia would probably just see a flat white surface.

Even if an environment is beautifully designed, a person with dementia who cannot process these inputs will have difficulty understanding this space. It makes them even more fearful because you need to understand an environment to be less fearful of it.

> *"We should ensure safety without being too over-protective."*

In that case, are there benefits to exposing persons with dementia to new and unfamiliar environments?

It is actually helpful for those with early stage dementia. Mental stimulation is helpful for a person with dementia. It may take a longer time and you may need to introduce something that is mixed — a little bit familiar and a little bit new. Mixing the familiar and unfamiliar will challenge them, but does not set the bar so high that it prevents them from trying. So one to initiate and the other one to continue.

As dementia fully progresses, are persons with dementia still capable of emotions?

Definitely. Emotions are not hindered by dementia, only processing is. In fact, emotions can be heightened, depending on whether or not we understand a given situation. Some of my patients with dementia exhibit heightened behaviour like fear or shouting when they feel confused in a given setting or situation.

Responding to someone with heightened behaviour involves empathy. We have to modulate their social environment, understand what provokes them and remove the stimulus. We should avoid provoking them as it could increase their anxiety level, causing them to respond negatively.

Are persons with dementia able to do things on their own?

Definitely. It depends on the severity of their dementia. For those in the early and moderate stages of dementia, they will still be able to do a lot of their activities. In fact, we encourage them to do things independently because you get stimulation from those activities.

People with mild dementia can even function in the community. I have mild dementia patients who still go to the coffee shop because they want to interact socially. They still want to buy their *kopi* from somewhere familiar. Having dementia does not mean that they have to stay at home and cannot go out.

However, as their dementia progresses, they may get lost in a new environment. This means that the community has to enable — and look out for — these persons. Someone can say, “Hey you are lost. Let me take you to a spot where we can call your loved ones.” So long as the social and physical environment is enabling, these persons can still function in the community.

> *“They still want to buy their kopi from somewhere familiar.”*

Do you have a “hack” — or smart ideas — to care for someone in the home environment?

It would be a good idea if we had a “walk in my shoes” session for designers or potential carers to better understand what a person with dementia experiences — in terms of visual, audio, spatial, tactile, or emotional sensations. It would help us understand people from other perspectives.

My wish is for a designer to understand and empathise with an older person with cognitive impairment to be able to better design for them. The best outcome is if a design can cater to both aesthetics and function — which requires us to consider their needs.

What would be a dream invention or device to care for someone with dementia?

Instead of the care recipient, I would think about the caregiver who is not cared for that well. I hope there is a device that reminds caregivers of their own stress level because they need to keep themselves emotionally, mentally and physically well to care for someone.

What final advice do you have for someone caring for a loved one with dementia?

My first advice for caregivers is to be kind to yourself. It’s very tough. Everyone is human and I think caregivers need to accept that what they are doing in caregiving is not an easy job. They shouldn’t blame themselves when the person they are caring for eventually deteriorates and cannot perform simple tasks. It’s part and parcel of the process.

My second advice is — it’s tough to be enabling and protective at the same time but we have to be both. I understand that the carer may feel bad if something bad (e.g. a fall) happens to the care recipient while pursuing an independent activity. We should ensure safety without being too over-protective. It’s about finding that balance.

My third advice is that people in Singapore read up a lot, but they should always discuss it with their doctor and other caregivers. Other caregivers have a life experience and it’s good to learn from their trials and tribulations. It is not just the physical act of caring that is challenging but also the emotional part.

Doctor’s Advice

1. Always discuss with your doctor and other caregivers.
2. Find the balance between being enabling and protective.
3. Caregivers, be kind to yourselves.

Mindfulness in Dementia Care

ERIC LIM, BRAHM CENTRE

PSYCHOLOGIST

Can you describe the work that you do with persons with dementia and their families?

I have been a Mindfulness Trainer with the Brahm Centre over the past five years. We conduct mindfulness classes to help people understand the habits of the mind and bring more awareness to themselves.

Caregivers often get stressed by negative thoughts about what the future may hold for their loved ones. Our 4-week mindfulness foundation course acquaints participants with the triggers that cause them to just "lose it." Stress causes the body to react — whether it is the shoulders getting tense or the heart rate increasing. When one is aware of these bodily signs of stress, he or she can respond appropriately.

Many participants have reflected that the mindfulness course helped them improve their relationship with the care recipient. While they cannot change how the care recipient is after getting dementia, they can change their own attitude — with that sense of acceptance, gratitude, and being kind. This course makes people aware of attitudes that empower them — so that they can care better for themselves and also improve care for their loved ones.

Can you explain what mindfulness is?

Mindfulness is about paying attention in a particular way — in the present moment, on purpose and without judgement. It is the awareness that arises when we choose to notice what's here. When we notice judgements arising within us, we can intentionally set them aside.

For example, my dad once gripped my arm very tightly and I instinctively pulled my arm away for fear that he would drag me. That was a natural reaction and in that moment, I judged myself, "Oh no, how could you do this to him?" With mindfulness, we notice what is here in the moment without judgements. I can tell myself, "Hey this happened and I'm okay with it."

Mindfulness allows us to tune in to what is here — like our bodily reaction, emotions or thoughts — and all these connect us to the present moment. Within that space of awareness, we now have a choice and can then decide how to respond.

How did you get started with mindfulness as a technique to cope with caregiving?

When I was studying Psychology at NUS, my professor introduced a module called Mindful Psychology. This module involved exercises like awareness of breathing, mindful eating, and body-scan practices that train our mind to re-focus on the body.

At the same time, my father had a stroke — which threw my life into disarray. The stroke limited his mobility and he came to rely increasingly on family members to get things done. It

> *"Mindfulness practice helped me gain awareness of what I had control over."*

was initially tough and I went through a period of denial.

Mindfulness practice helped me gain awareness of what I had control over. These included my emotions and "future-oriented" negative thoughts that arose. It helped me to stay more in the moment with my father. I also learnt to accept and let go of things I cannot control, like his medical condition. My father subsequently developed 2 other strokes and vascular dementia set in after that.

How should a caregiver introduce mindfulness into his or her everyday life?

It is really about having that space for self-care. As caregivers, we spend a lot of time caring for others. As a result, we often get tired in that journey and neglect ourselves. Mindfulness practice is about taking care of ourselves by tuning in to how our body feels. So if the body is really tired, we need to make that call to say, "I need a break." This means letting go instead of pushing through — which may lead to unintended consequences. For example, if we were feeding someone while feeling sleepy and tired, we might do something wrong.

Tuning in to our mind and body allows us to feel a sense of presence. This is important when we care for a loved one. For example, putting my phone aside would allow me to be fully present when tending to my father, instead of being distracted by notifications. It really helps to notice whenever our mind drifts away and consciously reconnect it to whatever we are doing right now.

Can you describe some simple mindfulness exercises that one can adopt?

One exercise is the "dot-be" technique. First, you consciously tell yourself to stop whatever you are doing. Close your eyes and breathe — and consciously invite this awareness into the body. Try to sense this awareness with your breath. It could be at the nose, chest or belly.

> *"Tuning in to our mind and body allows us to feel a sense of presence."*

Notice the breathing sensations — like your belly rising on the in-breath and just naturally let it go. You can then open your eyes when you feel ready.

Stopping like this — even if just for 30 seconds — helps the mind to settle and declutter, otherwise we will be in a fluster over what to do next. A caregiver's life is often hectic, with many things to do. But if we let ourselves pause, we will feel ready to do the next thing.

Another exercise is just eating, but with presence. During our meals, we can intentionally focus on the experience of eating itself by setting aside the distractions around us like the phone or the television. We can take the first few bites to appreciate what we are eating. Caregivers often share that just doing this helps them stay in the moment. It is one way to practise this sense of awareness.

Can you share an example of a family where mindfulness practice left a positive change?

This was last year when we held an 8-week mindfulness course at our centre. They came together as a family of 5 — the mother, the father, the daughter, and two sons. The mother had a certain medical condition that affected her speech and mobility and the family members were stressed. They came to the session with a lot of tension and anxiety.

As the 8-week journey progressed, how they communicated with each other started to change. This included choosing appropriate moments to speak and being open to listening as well. They felt less stress now and recognised when their minds rushed into the unknown future. Now they could guide themselves back to the present moment, knowing that they need to plan but need not get too caught up in it.

This helped them better attend to their mother's needs. Even while caring for her, they could also notice how they were responding to her — which was previously with frustration and denial. I saw this shift in attitude toward acceptance with a sense of gratitude. Rather than assign blame, the family members pitched in to help in whatever way they could. It was heart-warming to see them come together.

Mindfulness practice helped them be more aware of their habitual reactions and choose kinder actions and words.

> *"It is just a consequence of the illness, but that should not change our love for them."*

Can persons with dementia themselves practise mindfulness?

There is a continuum for dementia — from mild to moderate to severe. For those with moderate to severe dementia, it is probably not possible. This is because mindfulness practice harnesses the brain's pre-frontal cortex, which helps us with concentration. For persons with dementia, the pre-frontal cortex is usually affected. This explains why they get distracted very easily.

Those with mild dementia can try short practices. It wouldn't be 30 or 45 minutes, but maybe for 1 or 2 minutes. I have guided my father through a body scan before and he seemed more relaxed after the practice. We include persons with mild dementia in our workshops. It helps them to just notice or accept the new changes in their lives.

What distinguishes families that cope more successfully than others when caring for a loved one?

Family support is the number one thing. Caregivers who have attended our course share that they feel very alone in this journey, even within the family unit. Relatives may come visit but because they are not the 24/7 caregiver, they may see things a certain way and make comments that caregivers may disagree with, causing frustration.

Families that make it work for them have very strong mutual support. In these families, communication is open and they are not afraid to ask for help. I notice that this group is able to surf the wave of stress that comes with caregiving. They are open about whatever comes their way instead of fearing that it may seem shameful. The openness and courage to be vulnerable makes a difference. Families that welcome that often thrive better in that journey of caregiving.

What is your favourite hack — or smart tip — for caregiving?

Going for a walk alone in the company of nature. While caring for my dad, I sometimes got so frustrated that I needed a break. I would then leave home for a 10-minute walk outside. It need not be a walk. Sometimes, I would just sit outside the front door and look at the trees. It helps me refocus my attention and take time to rest. The hack would be that if things seem too challenging at that moment, it is alright to step out to give ourselves that "me-time."

> *"It is alright to step out to give ourselves that 'me-time.' "*

What would be your dream invention or device for caregivers?

My dream device would be a reclining wheelchair that provides the same comfort as an air mattress or hospital bed. I was once asked what dream I wanted to fulfil for my dad and I replied that I would like to bring him out.

Because of his condition, he has to stay at home and lie in bed most of the time. All he sees is the white wall and the ceiling. It is not easy to transport him around. Imagine if we bring him out on this device and he needs to rest. You just press a button and the wheelchair reclines into a comfortable bed that is still mobile — that would be nice.

One challenge for caregivers is that while we want to bring our loved ones out, there are limitations to how the place can support them. The care recipient may need to rest during the visit, or you have to feed them but do not have the accessories or environment to accommodate that.

I brought my father to the Sea Aquarium and they very kindly accommodated our visit. They raised the temperature and even brought a hospital bed into the place itself. We stayed there for the night and he watched the fishes swim by. That was probably his most memorable night. I knew he would appreciate it.

That leads me to the other hack which is to bring them to an aquarium. For bed-bound care recipients, the home environment is literally a prison. Their eyes feast on the walls or the television and that's all to it. A dynamic environment with something that changes would help them pass each day with a sense of freshness injected into it.

▶ Visit www.brahmcentre.com to find out more about mindfulness.

What final advice would you give to families caring for a loved one with dementia?

I would say that the care recipient is still the same person despite whatever behavioural challenges he or she might pose. It is just a consequence of the illness, but that should not change our love for them. We should cherish those moments even if it is difficult — because things change and the difficult moments will not last all the time.

At those moments when the care recipient is like himself or herself, we can stay present and savour the moment while it lasts because we will really never know when that might change. I really appreciate all the caregivers out there. Without them, the journey would be a lot tougher.

Eric's Guide to Mindfulness

1. **"Dot-be" technique.** Stop whatever you are doing. Close your eyes and breathe. Sense an awareness with your breath, and let it go. Open your eyes when you feel ready.

2. **Be present during mealtimes.** Set aside the distractions around us. Take the first few bites to appreciate what we are eating. Focus on the act of eating.

IT TAKES A KAMPUNG

Don’t walk the journey alone.

It is okay to ask for help — caregiving becomes easier with many helping hands. Involve the whole family, and perhaps even your neighbours. It makes a world of difference.

Hacking is not rocket science

ONG KER-SHING, LEKKER ARCHITECTS

What are important things to note when caring for a person with dementia?

It's often said: Treat the person, not the disease. It is easy to understand, intellectually, why we have to remember the person who has dementia, and not to allow caring for a person with dementia to slip into a disease-management model of care. And sometimes this is incredibly difficult, and challenging, and the caregiver(s) really needs to be kind to themself if they lapse into automatic behaviours of care. To have a loved one suffering with dementia is already torment in itself, but to add constant guilt on top of that is too much.

The caregiver needs to remain sane and healthy as well, so that they can really be there for the person with dementia. Because dementia is a progressive disease, the conditions are really dynamic, they are constantly changing. There might be some plateaus but then there is always, inevitably, deterioration. Caregivers need to be able to see these changes and adjust accordingly: adjust the way they speak, the kinds of things they need to do (like whether they need to switch from drinking water directly from a glass, to a straw, to even a syringe), the texture of the food they make, the amount of independent activity and other emotional and relational expectations they have of the person with dementia.

Caring is active and requires constant observation and evaluation and being in the moment. It is ironic, because at the onset of dementia, what we notice the most is loss of memory—and painfully, the loss of common memories made together—that family members of a person with dementia often focus so much on the loss of a past and the loss of a future together. But it is the ever changing present that is where we need to be. Carers quickly learn to become clever problem-solvers and hackers. Being a hacker is not necessarily rocket science, it is making small tweaks to things that already exist, that we already use, to suit a new need. Small adjustments also allows for a familiar situation to persist whilst adjusting as necessary to minimise danger, increase comfort and happiness, et cetera.

What are important triggers to avoid when caring for a person with dementia?

I think this really depends on the individual. From my own observation, the "pre-morbid personality" of the person with dementia plays a huge role in the disease progression, or at least the behavioural manifestations of the disease as it progresses.

For example, my father was always a very independent person. He was brilliant, authoritative, proud, a problem-solver. This made it very difficult for him to accept, in the early stages of the disease, that he had a problem that he would not be able to overcome. It also made it very difficult for him to

> *"Carers quickly learn to become clever problem-solvers and hackers."*

accept help, especially from his own children. My good friend's mother, on the other hand, had always been more dependent on her husband and children to do things with and for her. With her dementia then, she was willing for her children to take over her house-work and even personal care.

Can persons with dementia do things for themselves?

Yes, in the earlier stages, certainly. It is crucial to allow the person with dementia to do as much as possible for themselves, to retain their sense of dignity and self for as long as possible.

Are there ways to help persons with dementia experience more joy and delight? Do you try to recreate sensations that the care recipient likes?

This gets difficult as the disease progresses, because certain things just can no longer be done because they become dangerous, like, eating ice, for example. Also, it becomes harder and harder to know whether something is delightful or whether the person is enjoying themselves any more.

So I find that at the advanced stage of the disease, which is where my father is now, we have to rely on some more "universal" ideas about what is joyful, like taking him to sit outdoors in the garden in the shade when there is a cool breeze blowing, or stroking his arm, or just putting a hand on his shoulder, as touch is so important for well-being.

I think sometimes we have to use common sense and empathy. Like when the person with dementia has to eat blended food because they are no longer chewing properly: do we blend it all up into a big pot of mush? Or do we blend or mash individual components of the meal so that there is still some discrete tastes: steamed broccoli still tasting of broccoli, fish tasting of fish…

> *"Combine compassion, common sense, and own gut instinct and just do your best."*

Can you share with us your favourite caregiving hack?

There was a while that my father would only drink water out of one glass. As his dementia progressed, he would only recognise water if it was in that glass. We only had one of those glasses, so it became a bit difficult if say, Dad was at his sister's house for lunch, and would not drink water as a result. Luckily, IKEA has such a huge range of glasses, so we found something almost identical there. We bought a box of 6 of them so we could put a couple at my aunt's house, and a few around our house, so the water-drinking issue at that time was solved.

What is your favourite IKEA product for caregiving?

It's such a simple one, really. We love using the IKEA shower curtains as mattress protectors. They are large, so they are easy to tuck into beds, they are completely waterproof, and they are cheap.

How do you — and other caregivers in your family — look after your own needs?

We are lucky as we are a big family and we have a couple of amazing helpers who have been with us for years and years. This means that there are separations of duties and each person can do what they do best. All the duties, responsibilities, and emotional weight of caregiving do not lie only on one person's shoulders. We each contribute in the way that we can, and that we do best. I find that in our family, this is the most sustainable way. It also means that the person ultimately making the big decisions and managing the care can appeal to a relatively (major emphasis on relatively) objective state when it is needed.

What is the most important thing you have learnt in this caregiving journey? What advice would you offer to other caregivers?

In addition to everything I've said above, really that there's no right and wrong. Combine compassion, common sense, and own gut instinct and just do your best.

What would be a dream invention or device to care for a person with dementia?

Caregiving can become all-consuming. I would love a magic hat carousel that caregivers could put on and that helps them to switch channels as it were and see things from different points of view—points of view that might be hard to get to because the role and responsibility of caregiving is so all-consuming. It would help them to wear those proverbial different "hats" and gain some perspective, and some relief.

Shing's Hacks

1. Blend individual components of the meal to keep their discrete tastes.

2. Have multiple of their drinking cups around relatives/friends' houses. This helps them in their drinking habit.

3. Shower curtains make good mattress protectors in the event of incontinence.

▶ See page 162-163 for more tips and tricks on coping with incontinence.

LET'S GET CRACKING

Now that you've made it to the end of the book, it's time to get started on your hacking projects. Grab your tools and involve the whole family.
Let's do this!

DISCLAIMER

The ideas in this catalogue have been gathered to suggest ways to improvise and expand care for persons with dementia. While every effort has been made to ensure that the hacks contained in this catalogue do not pose any undue health and safety hazards, we nonetheless urge all readers to exercise their own judgement on the safety, suitability and appropriateness of these ideas to their own respective caregiving situations. Readers are encouraged to do their own research, and to always consult a professional when in doubt.

HACK CARE is a social initiative led by the Lien Foundation and is not related to IKEA®, the Inter IKEA Group, or the Ikano Group. All references to IKEA® products are presented for the reader's convenience only and do not imply IKEA®'s approval of the modification of their products. IKEA®, the Inter IKEA Group, the Ikano Group, and the team behind HACK CARE shall not be liable for any product failure, damage or personal injury resulting from the use of the hacks featured in this catalogue.

You can do it yourself, and we're here to help you.

Here are 8 quick-start tips.

MAKE IT YOUR OWN

There is no right way to hack an object or environment. Adjust it to your own needs; do it your way.

A SMALL TWEAK GOES A LONG WAY

Hacking your environment doesn't have to be complicated. Sometimes all it takes is a tiny adjustment to make life easier.

HAND EXERCISES HELP THE BRAIN

Encourage them to use their hands. It stimulates the brain and resists the onset of dementia.

DURABLE & UNBREAKABLE

Material matters. Choose sturdy and hardy materials to ensure safety, and you'll never have to worry about breaking anything.

IT'S ALL ABOUT THE CONVENIENCE

Pre-packed kits are one trick. What are the other mental kits to organise your life?

ROUTINE AUTOMATES

Externalise tasks into reminders and habituated actions to reduce the burden of remembering.

MAKE IT COLOURFUL, MAKE IT POP

When we see things clearly, it makes life easier to live.

MULTIPLES OF THE SAME MAKE LIFE EASY

Keep back-ups of their favourite or frequently used items. It's always a good idea to have a plan B, and C, and D...

Don't forget to have fun.

About the Lien Foundation

We are a Singapore-based philanthropic organisation guided by a 'radical' approach to tackle problems at its roots. We view innovation as a permanent state of exploration, and embed design into our work in early childhood development, eldercare and end-of-life issues, as a key driver of value creation. Social problems are not isolated fragments that can be unpicked or solved with a hammer chipping away at the marble. Often, we find them tethered to the fabric of society's long-held assumptions, scraps of archaic practices and ingrained patterns of thinking. It is this reason we turn to design to recast our thinking, to orientate towards shaping new experiences and behaviour, as well as to focus on fresh approaches and solutions.

Our catalogue of design publications includes Hospitable Hospice, a handbook which offers universal concepts and design principles for future hospices, with the aim of improving the end-of-life journey. A Different Class showcases 10 typologies of preschool spaces, while Second Beginnings presents 10 new architectural concepts of community spaces for seniors. Others have taken a leaf off those pages and incorporated those ideas in actual projects. From blueprint to the built environment, we developed a "living classroom", based on the laboratory school concept, for trainee teachers to observe lessons and complete their practicum and research. Singapore's first purpose-built inclusive preschool was subsequently conceived, allowing children of all abilities to grow together in a supportive environment. We also reimagined play by getting designers to work with children and teachers to hack an existing playground and create their own play space.

With the vision of ushering in a new era in eldercare, we are spearheading a number of innovations, including a residential care facility for people with dementia which has an onsite lifestyle club and day activity centre for the community. We also started Singapore's first dementia-friendly community to ignite public awareness and expand the network of dementia friends. In the pipeline is a dedicated, dementia-friendly social space for seniors within a museum. It will offer curated programmes that leverage digital technology and facilitate inter-generational experiences on Singapore's history and heritage. To combat frailty among seniors, we are developing a chain of gyms for seniors in the community, designed to be vibrant social hubs.

Design holds great promise to solve the most pressing challenges of our time. We conscientiously embrace the emerging possibilities afforded by new technologies, and hope to engender a new breed of designers as catalysts for change in our ecosystem of partners and projects.

www.lienfoundation.org
www.facebook.com/JourneywithGeorge

IT'S OK TO ASK FOR HELP

There's no problem too big, or too small, that the community cannot fix. If you're ever feeling lost and helpless, or simply just tired, don't hesitate to reach out to support groups for guidance. It takes a village, and it's only a phone call away.

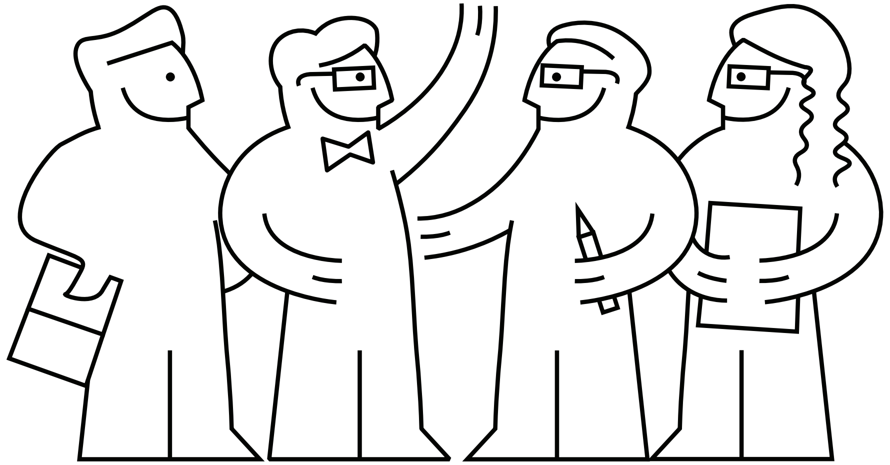
Some useful resources:

Alzheimer's Disease Association (ADA)
To find out more about ADA's dementia care, call the Dementia Helpline at 6377 0700 or visit www.alz.org.sg for more information.

Brahm Centre
Find out more at www.brahmcentre.com, or drop them an email at info@brahmcentre.com. Alternatively, visit any of their 3 centres: Novena, MacPherson or Simei.

Forget Us Not
To access a series of 50 Caregiving Videos, please visit: www.forgetusnot.sg/videos.html

THE HACK CARE TEAM



01 Lee Poh Wah Lien Foundation.
02 Gabriel Lim Lien Foundation.
03 Ivan Loh Lien Foundation.
04 Radha Basu Lien Foundation.

IT'S ALL ABOUT TEAMWORK

HACK CARE is the result of the combined efforts of the Lien Foundation, Lekker Architects and Lanzavecchia + Wai Studio. Each of the persons named here was instrumental in bringing this book to fruition. We also thank Ruth Wong, Eric Lim and Dr. Wong Chek Hooi, for generously sparing their time to offer their insights and wisdom.

Lien Foundation

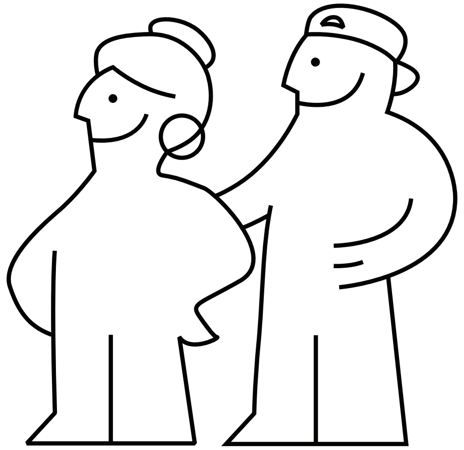
Lien Foundation is a Singapore-based philanthropic organisation that seeks to inspire social change and improve the lives of seniors, children with special needs and those who are born into low-income homes.

Lekker Architects

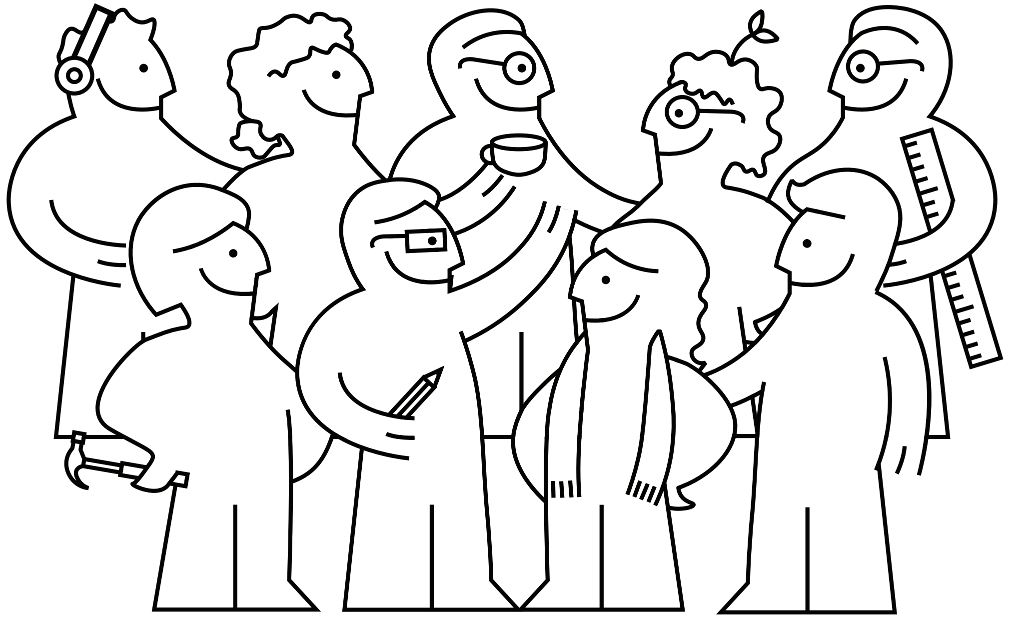
Lekker Architects is a Singapore-based group of designers, architects, and social scientists whose interest lies in projects with big ambitions: from buildings that promote inclusion, neighbourhoods that encourage walking and socialising, to dreamlike retail experiences that are exciting and transformative.

Lanzavecchia + Wai Design Studio

Lanzavecchia + Wai Studio is a multi-award winning industrial design studio based both in Singapore and Italy. To them, being designers means being researchers, engineers, craftsmen and story-tellers all at the same time.



06 Francesca Lanzavecchia Lanzavecchia + Wai Design Studio.
05 Hunn Wai Lanzavecchia + Wai Design Studio.



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