

THE HEART AND SOUL OF CAREGIVING

It's important to be informed about the practical side of caring for a loved one while keeping the family together. What are the different roles and duties between a family caregiver and a professional caregiver? Caregivers share their experiences about caregiving and what they've learned along the way.


Caregiving is a labour of love. A caregiver provides physical, emotional and practical care and support to an ageing or ailing person while managing their own life, needs, family, and career. Caregiving covers helping with important activities for daily living such as feeding, bathing and dressing, paying bills, and providing transportation. It may also involve emotional support and help with

managing a chronic disease or disability.

There are two types of caregivers: family caregivers who volunteer their time, without pay, to care for a loved one and professional caregivers who are hired to provide medical or non-medical care to patients either at home or in a facility.

Family caregivers are usually the backbone of long-term care for the patient. Depending on the needs of the person being cared for, caregiving may take more than one person. It can include family members, professionals (from a home care agency), community support (church members, neighbours),





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and friends. The tasks of caregiving are wide-ranging, and they cover all need levels of the person who is being cared for. Being a caregiver can be exhausting, frustrating, and stressful. It can test our body, our emotions, and our spirit. It can feel like a never-ending task with little support and understanding from others, especially when we are a sole caregiver.

Despite all this, caregiving can be a rewarding and meaningful experience. It gives caregivers the opportunity to connect, show affection, support, and bond with their loved ones. You know your loved one is getting the best possible treatment and support because you are providing it.

A caregiver's life can be

affected in many ways, including his or her ability to work, engage in social interactions and relationships, and maintain good physical and mental health. The ability to delegate tasks to others and garner support is key. It is critical to understand the physical and mental health burden on caregivers and the range of tasks caregivers undertake.

SOLE CAREGIVER FOR A DEMENTIA DAD

“Dementia caregiving is very different from caregiving for the aged,” stresses Shamayne Leelawati. Being an only child, Shamayne is the sole caregiver of her 86-year-old father, who was diagnosed with vascular dementia 11 years ago.

Shamayne, a freelance editor, assumed the role of the main

caretaker after she got married and moved abroad. She had a helper she personally trained to assume the role as caretaker. She asked her mother (her parents are divorced) to come and stay to keep an eye on her father. She returned home four times a year to manage his doctor appointments.

When the pandemic hit in early 2020, Shamayne made it home in time before the global lockdown and became the sole caregiver of her father.

“All the while, I had a system going on in caring for my dad. But at the first MCO (movement control order), everything came to a halt. None of my helpers could come to our home, so I had to single-handedly care for my dad,” she says.

While some families require a caregiver to give basic physical care to the patients, Shamayne wanted the best for her father and had drawn out a comprehensive dementia care plan for him that would require more effort on the part of the caregiver.

Even during the MCO, she never slacked in carrying out the plan. The daily routine incorporated indoor and outdoor exercises, playing some word games, watching television and listening to music, and times of relaxation and rest.

"My objective is to keep Dad feeling comfortable, assured, safe, and secured. And the programme that I had planned for him contributed to that," she says.

However, the lockdown period turned out to be not only a difficult but even a traumatic time for Shamayne, who had to attend to all the household chores as well as taking care of her father.

"You can't even watch TV and rest for a moment. Every five minutes, my dad would say, 'I want to go home' as he didn't know that he was already at home," she says, adding that her dad has Sundowning Symptoms. His restlessness, agitation, and confusion worsen as daylight begins to fade.

"You need to be patient but also need to know how to handle the Sundowning Symptoms. He would get up in the middle of the night, and he has urinated in the laundry basket many times

thinking that was the toilet. He didn't know what he was doing," she says.

Her dad would wake up at 5:30 or 6 in the morning and Shamayne had to be up to care for him. It was very tiring and exhausting for her. It was a 24/7 job, and in between she still had to do laundry, cook, clean and do marketing and other household things. And she was still trying to hold on to her freelance editing job.

"I was completely worn out, and I had no support from anyone. It was at least eight months later that I finally got back a helper," she says. She is now back in Bahrain and has employed two helpers: one for the day and one for the night shift to care for her father.

During the MCO, Shamayne took the afternoons when her dad was resting to educate herself further on how to care for dementia patients. Her determination and diligence saw her eventually

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taking eight courses and receiving her certification as a Dementia Care Specialist. She is also a mental fitness coach.

She now reaches out to families, assisting them in their caregiving journey whether it is creating a personalised care plan, guiding them on a person-centred approach in caregiving, or providing emotional support to caregivers.

"Caregiving takes sacrifices from your time, work, and other areas of your life. Most Asian families prefer to keep their loved ones at home, and it's always a very emotional journey for family caregivers. Depending on circumstances, we sometimes need to turn to professional help as we may not be able to care for them well enough at home," she says.

FROM HOME TO PROFESSIONAL CARE

Yvonne Lee and her siblings had to make the difficult decision to send their 75-year-old mother, who was diagnosed with vascular dementia, and her 81-year-old father to a nursing home.

"When Mum was first diagnosed with vascular dementia, we researched about the condition and learned more about the trajectory of dementia so that we had an idea of what to expect as the illness progresses and how to care for Mum," says Yvonne, the eldest of three. She has a brother who lives in Singapore and a sister, Janet, a jazz singer, who is her joint caregiver.

"After the diagnosis in early 2020, we relocated both parents from



VOCATION OF CARE AND DEDICATION

Norsharipah aka Sherry Lokeman, a care professional from Homage Malaysia, shares her experience as a professional caregiver.

"For three years, I cared for my mom who was suffering from osteoporosis and occipital stroke where she had limited mobility. She was also diagnosed with dementia. My time caring for her made me realise my potential to contribute to caring for the sick and elderly and striving for a better wellbeing in society.

"Besides my personal experiences of caring for my mom, I started learning caregiving online. I then registered with Homage, where they provide training and courses to become a certified caregiver in collaboration with Sahara Academy.

"At Homage, we serve people with disabilities, mental illness, people who are chronically ill (e.g. diabetes, renal failure), older persons who have difficulty coping with daily living, and people who are terminally ill. We care for them in various aspects from check-in visits, companionship, meal arrangement, and personal care and hygiene to toileting and night care. My top priority is to ensure they are comfortable in their day-to-day living.

"My day starts with my patients—where I check and change the soiled adult diaper, and shower or bed bath them depending on their mobility. Next is making sure their meals are served on time and also assisting with medicine prepared by the family. I will then check on the patient's blood pressure, blood oxygen levels, sugar reading (diabetes), etc. and record them. This is followed by Range of Motion (ROM) exercises. I accompany care recipients with ambulation (the act of moving about and walking) and teach them how to use appropriate walking aids. I also get them to do mind-stimulating activities like word games, puzzles, card games, chess, and strategy.

"Professional caregivers should be able to adapt to many areas in caregiving. Caregivers need to build trust and should be able to deal with situations at hand, and boundaries shouldn't be crossed. Understanding the patient and giving her/him the attention needed is an important aspect of caregiving.

"For example, do not see the patient's behaviour as symptomatic as their behaviour is the result of a disease. If you're about to respond emotionally to the negative behaviour of the client, step back and re-approach him or her later. Ask yourself if there is a way to problem solve and help the patient communicate or react differently.

"Not everyone can be a caregiver due to a lack of experience, caregiver burnout, and availability of doing so. Realistically, family members have to earn a living, and we as caregivers take away the burden of caregiving so that they can best support their loved ones by other means and ways.

"I think many Malaysians still don't know what the caregiver's role fully entails as the exposure is not there yet. Formalising caregiving is a norm in countries like Singapore, Japan, Australia, and the USA. I hope one day Malaysia will be at that stage where caregivers are appreciated more because our roles are beyond just the physical aspect of care but also tap into our mental and emotional capacity."



FEATURE

Taiping to Kuala Lumpur so that we can monitor them closely. Janet and myself took turns to cook for them, clean their apartment, provide cognitive stimulation for Mum, and bring them to the doctors.

"My Mum also attended a day care centre for people living with Alzheimer's and dementia at a centre called ADFM (Alzheimer's Disease Foundation Malaysia) in Petaling Jaya from Monday to Friday. That was a respite for us and Dad, and the centre does a fantastic job in providing physical activities and mental stimulation for elders with dementia," she says.

However, by September 2021, her mom's condition worsened and she had trouble sleeping

through the night. Her night pacing started, and she had also fallen at night due to balance problems while walking. As her motor skill deteriorated, she needed assistance in basic living, such as bathing, walking, and feeding, and she was weaker too.

Yvonne and her siblings came to a decision to have their mother live in a nursing home since it offers 24/7 care, with their father accompanying her and overseeing the caregiving rendered by the staff in the home.

"Sending our parents to live in a nursing home is one of the toughest decisions we made. It took us three months of scouting and having visited 26 homes in PJ before we found one. As much as we want to keep Mum

at home and get her a live-in caregiver, there were many issues, mainly finance and the risk of the caregiver leaving at short notice. During the lockdown, it was also very hard to get a foreign caregiver and the maid agency fee was exorbitant," she says.

"As the elders' needs change, how well the family caregivers or staff of the home can cope with their needs truly makes a huge difference, she says. In a nursing home, there's a team of staff who can provide different levels of assistance. For her mom, a night shift caregiver is crucial because she wakes up at night, and someone needs to watch over her.

"Besides assisting in their physical and medical needs, the home also provides some activities and companionship. Patients are monitored constantly and most importantly, in emergency, there's someone there.

"The caregiver updates me often with photos, and I feel assured that there's someone to watch over her at night. There are regular doctor visits and a physiotherapist to help her in improving her movements," says Yvonne.

Due to the close proximity, Yvonne drops by almost daily to run errands for her dad, and she brings her parents meals they like to have. Her sister, who lives further away, makes time to go in two or more times a week. They regularly pick their parents up for car rides and sometimes go to Yvonne's house for a meal.

"The advantage of very regular visits gives my mum the assurance that she's not being abandoned," she says. ●



A PRACTICAL GUIDE FOR SIBLINGS WHO SHARE CAREGIVING FOR AGEING PARENTS

When you're caring for your ageing parents, you can use all the help your siblings have to offer. Your brothers and sisters can provide a tremendous amount of support, but there may also be challenging family dynamics to manage.

Learn how to lighten your load and draw your family closer together by sharing caregiving responsibilities with your siblings. Try these strategies for working together as a team.



MANAGING LOGISTICS

- 1 Hold family meetings.** Even if your family is spread out over long distances, try to gather in one place. Talking about how to care for your parents before an emergency arises allows you to approach the subject with a clearer head.
- 2 Assign roles.** It's easy to drift into old patterns. The child who was labelled the responsible one growing up may automatically assume much of the decision making. Instead, each of you can look at your current capabilities and contribute accordingly.
- 3 Consult professionals.** Ask family physicians, pastors, and friends to help you find the resources you need. Engage a geriatric care manager to coordinate the process.
- 4 Share information.** Talk with your brothers and sisters about what you learn as you research issues about ageing and caregiving. Give each other updates after you call or visit your parents.
- 5 Maintain records.** You may need to deal with some complicated medical, financial, and legal arrangements. Proper documentation can prevent misunderstandings and help you comply with applicable laws.
- 6 Encourage independence.** It's important to remember that your mother and father want to maintain their independence for as long as possible. Look for ways to assist them that support their dignity. Installing safety bars around the shower is one adjustment that helps them care for themselves.
- 7 Ask for help.** Call on each other when you need a hand. Be factual and specific. You can let your brothers and sisters know that you need them to cover part of a medical bill without trying to make anyone feel guilty.

MANAGING EMOTIONS

- 1 Think about ageing.** Watching your parents grow older may trigger uncomfortable thoughts about ageing and death. Join a support group or read spiritual material that can help you understand your feelings.
- 2 Sort out rivalries.** You may find yourself competing for your mother's attention or reliving old memories about how your father took your brother camping without you. Decide to let go of past conflicts, or talk them over with your siblings.
- 3 Respect differences.** Each member of the family may have different opinions about the situation and unique ways of contributing. Accept that your sister may be more willing to pay for a gardener than to come over on weekends to do the yard work herself.
- 4 Establish realistic goals.** It can be difficult to juggle caregiving on top of all your other responsibilities. If you're becoming overwhelmed, concentrate on the essentials.
- 5 Express compassion.** This can be a challenging time for the whole family. Be gentle with yourself and your siblings as you take on new tasks. Let your parents know how grateful you are for the love and guidance they've provided.
- 6 Take a break.** Taking time off will help you sustain your strength. For example, ask your parents if they'd like to take senior aerobics classes at the local gym so you can spend Saturday morning with your kids.

As the average lifespan increases, you may be able to enjoy your parents' company for many more years than you expected. Advance planning and skilful communication will help you and your siblings to collaborate on caregiving to make this stage in your family's life more joyful and meaningful.