Empowering caregivers to support more caregivers

Have you ever wondered who cares for the caregivers of persons living with dementia? Looking after loved ones can get overwhelming at times — as Madam Salmah Roslan discovered when her mother was diagnosed with dementia seven years ago.

Thankfully, a friend directed her to the **Caregiver Community Outreach Team (CREST CG)** at Club HEAL. Set up to support caregivers like Salmah,
CREST CG actively promotes caregiver self-care through health and
wellness activities, stress management, and future planning.

Today, Salmah shines as a Caregiver Advocate at Club HEAL, where she is dedicated to building an uplifting community for caregivers. Here's how Salmah and Mr. Zainal Abidin Lee, Head of the CREST CG Club HEAL programme, help people in their caregiving journey.

Why is self-care important for caregivers? What are some things they can do?

Zainal: Caregivers look after their loved ones without realising that they, too, need support on their caregiving journey. The CREST CG Club HEAL programme provides that support by organising activities, facilitating support groups and psycho-education on caregiving, and most importantly, by lending a listening ear.



How does CREST CG reach out to caregivers?

Zainal: When we first launched CREST CG, caregivers did not understand how CREST CG could help them. So I called up all the caregivers I knew and spoke to them one-on-one to explain why self-care was so important for caregivers.

It yielded good results! Having this face-to-face connection keeps the programme thriving. We now have a steady group of caregivers attending our programme.

Salmah: When my mom was diagnosed with dementia in 2016, it was all so new to me. I knew nothing about dementia. That's when a friend told me about CREST CG. I met with Mr Zainal, who shared available caregiving services, and introduced me to the CREST CG programme.

I immediately enrolled! I wanted to take care of my mother and myself in the best way possible to ensure her happiness. I definitely achieved that through my experience in CREST CG.

What advice do you have for caregivers?

Salmah: At CREST CG, we listen and share about our loved ones and our experiences to feel less alone. This empowered me in the past and now I wish to help others too by sharing my story. Hence, I became a Caregiver Advocate to encourage other caregivers to participate in our activities that emphasise the importance of self-care.

As a caregiver, people believe and trust my experience. I also did my own research and attended the Healing Friends Training (HFT) course for caregivers. This helped me learn how to overcome grief and to prepare for the future — important information that I share with others.

46 You have to take care of yourself before taking care of others.
99

Madam Salmah Roslan Caregiver Advocate, CREST CG Club HEAL programme

Zainal: Caring for your loved one is important, but so is caring for yourself. That's why CREST CG exists, to support those who are devoting time and energy to their loved ones. You can come to us and we will be there to support you!



Reconnecting families through love in their care journey

Persons living with dementia can display challenging behaviour or pose challenges due to the condition. That is why the **Dementia Care System (DCS) Team** plays an important role by providing professional help and intervention to support caregivers.

As the sole caregiver for his wife who is living with dementia, Ben* struggled to juggle his caregiving responsibilities with his own recovery from a fall. Thankfully, the DCS team under the Tsao Foundation stepped in and helped the couple to find hope and assurance in their care journey.

An allied-health team for an individualised care plan

Led by an allied-health team of a medical doctor for case consultations, registered nurses, social workers, counsellors, assistant care managers and dementia care programme assistants, the DCS team develops individualised care plans tailored for individuals. These include personalised consultations and building a long-term support network caregivers and patients can depend on.

"It takes many hands to support clients living in our community," says Yong Leong Ying, a Clinical Lead from the DCS team.

To help Ben and his wife, the team visited their home and got to know them. Through these family consultations which included their children, they conducted a nursing, social and spiritual assessment to ensure the care plans they proposed were tailored to the family's needs.

Building up rapport this way also helped to make Ben and his wife more receptive to the team's proposed care plans. They explored recommended activities such as the day care centre and Active Ageing Centre [AAC] services nearby, and even entertained the idea of hiring a domestic helper, which they had vehemently refused before.

This trust yielded more revelations. Ben's wife revealed that she had acted out of a yearning for love and connection, which Ben, deep in his anxieties, had been unable to see. The team counsellor helped guide their journey from grappling with grief and loss to a new love language born from their shared experience.

For Ben and his wife, the caregiving journey is no longer filled with hardship, but a path to love and self-discovery.



It is important to know the person living with dementia as who they are and not their behaviour, to appreciate where they are and to understand their challenges.

Yong Leong Ying Clinical Lead, DCS

Empowering patients through people-centred care

Families like Ben's remind Leong Ying of her aspirations in joining the mental health sector.

"We focus on people-centred care to help our clients develop the knowledge, skills and confidence they need to make their own decisions," says Leong Ying. "Building security, psychological safety, and assurance helps us make care less scary for patients and caregivers."

The community has a part to play as well. "By fostering a community that engages and builds rapport with dementia patients, we can achieve more, empower patients, and advocate for their needs as humans."

Enabling meaningful caregiving journeys and better understanding

As seen with Ben's journey, the DSC team also fosters positive interactions and helps families navigate complex relationship dynamics.

"The caregiving journey can be stressful and tiring, so relationships can get tense at times," says Chai Li Yen, a Dementia Care Programme Assistant.

After all, clients are not just their diagnosis, they are people. The DCS team reminds caregivers to take that into account, and be more understanding when caring for their loved ones.



Love always wins. Sometimes, we just need to be reminded to make the caregiving journey more joyful.

Chai Li YenDementia Care Programme Assistant, DCS

"We try to be the bridge between caregivers and clients," Li Yen emphasises. "Caregivers are so stressed from caregiving that they can forget about the good times spent with their loved ones. We lend them a listening ear, prompt them to recall the sweet memories they shared during happier times and remind them they are 'family', not 'client and caregiver'."

"Ultimately, the key is to tell them it is okay to be frustrated sometimes, but they should see this caregiving process as a joyful journey, allowing their loved ones to live the best life they can, rather than as an unwanted responsibility."

Li Yen finds her role especially meaningful as she can help caregivers and patients to reconcile and embrace their journey ahead. She muses, "If they have a good relationship and the intention is good, how can they bring this care and love into the caregiving journey?"

*Names have been changed to protect the identities of clients.





Dementia won't erase you: a love letter to my dad

"You're a good son, Daniel." Coming from his father who rarely verbalised his affection in the 40-plus years they've lived together, these simple words mean the world to Daniel Lim — and make his sacrifices all feel worthwhile.

For the past 15 years, Daniel has been the main caregiver for his parents. In 2009, his mother was diagnosed with cancer — and his father, dementia — in the space of a month. The only child realised that, at age 29, his life was about to change drastically. He would not be able to work overseas, get married, or move into his own home. After all, he rationalised, who would want to share such a heavy burden with him?

Fast forward to the present, and Daniel has learnt to thrive in his caregiving role, lean on the support of his relatives, friends and neighbours, found love, and even started a social enterprise, Enable Asia. By sharing his personal story, he hopes to inspire, empower and improve the lives of persons living with dementia and their caregivers.

One thing he would like to assure everyone is: there is joy to be embraced in the journey.

Here, Daniel counts his blessings in a letter to his father.



Co-founders of Enable Asia, Daniel Lim (L) and Danny Raven Tan (R).

Dear Daddy,

When you and mummy were diagnosed with your illnesses 15 years ago, I felt like I had been thrown into the deep end of a pool. I was lost and alone, and did not know where to turn to for help.

We were in a tough situation, both financially and emotionally. I felt stressed and resentful, and even thought of ending it all.

Thankfully, I had the opportunity to connect with other caregivers who were going through similar struggles. I felt greatly comforted to know that I was not alone. This inspired me to start Enable Asia to support fellow caregivers, and since 2018 we have been organising the Enabling Festival every year to raise awareness of what it means to live with dementia.

Daddy, I know these past years have not been easy for you either. Thank you for continuing to care for me as your son, even as you are learning how to live with dementia.

Thank you for pointing out what I've been doing wrongly so that I can learn how to do better. Thank you for reminding me to continue treating you with dignity and respect, and for opening my heart to see and appreciate the person behind the condition.

Thank you for all the friends I've found and for the support I've received along the way. I once thought that this responsibility was for me to bear alone; now I've discovered that asking for help only makes me a stronger person.

Mummy and I will always love you! Thank you for helping me to find my purpose in life. Thank you for letting me care for you. Thank you for being my father!

Always your son,

About Enable Asia

Enable Asia is a social enterprise that is passionate about enabling persons with dementia to lead a life of dignity and grace, while providing support to their family caregivers through art, design and technology.

It organises the annual Enabling Festival to share resources, activities and programmes with persons living with dementia and their caregivers.

The Enabling Festival 2023/24

This year's Enabling Festival will make its next stop at Jurong Regional Library from 2-31 October 2023. The 6th edition of the festival showcases the sensory power of Smell for persons living with dementia and their caregivers through an interactive and roving exhibition, Scented Stories.





HELPFUL RESOURCES

'Lady!' documentary

Imagine losing your husband's independence to early onset dementia when he is 50. 'Lady!' is an intimate documentary that chronicles the bittersweet journey of a young, devoted wife as she cares for her spouse.

With the support of community organisations, 'Lady!' is slated to be screened to healthcare professionals, patients, caregivers and the public. Follow the team on Instagram (@ladythedoc) to keep updated on upcoming screenings!

If you are interested in hosting a private screening, please contact Kelly (9769-8418) or Ee Ming (9680-0257).





Dementia Hub event calendar



Stay on top of the latest events and happenings at the Dementia Hub website. Browse, search, and register for upcoming activities and seminars easily using the updated event calendar.

View upcoming events:



More dementia Go-To Points (GTPs) islandwide



How can we help persons living with dementia who seem to have lost their way? One way is to guide them to dementia GTPs at designated MRT stations, bus interchanges, supermarkets, and other community spaces for assistance.

View the updated list of dementia GTPs:



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Email: ccmh@aic.sg

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Feel free to drop us an email (ccmh@aic.sg) if you would like to contribute content!