

Caregiving in Dementia - A Sri Lanka Narrative

By Dr. Deepthi Amunugama - As published in ADI's Voices from Asia- Pacific



Dr. Amunugama and his mother

It was around 2018 when the early signs started emerging. My gentle mother suddenly became suspicious of the housemaids. Initially, I just replaced them but then when her irrational behaviour persisted, realized it was due to mild paranoia. As a doctor, my medical training kicked in. I had her checked out by a colleague who is a psychiatrist and obtained a formal diagnosis and the necessary treatment. Soon, however, she began to show additional symptoms which were further exacerbated by my father's illness that saw him bedridden, for a short while, before he passed away.

Theoretically, I was well aware of what to expect and the natural progression of the disease. Despite all of which, my mental reaction as a son and the main caregiver took centre stage. I questioned why this calamity had to happen to my mother who has served for years as a government servant, managing one of the largest oncology units in the country. Had she not survived and overcome cancer and been in remission for over 30 years? I went through the entire gamut of emotions that I believe all family members of dementia patients go through. The knowledge and understanding of what to expect did not make the burden of the illness any different or less.

Even as I struggled with the emotions and depression that family members often face in light of a dementia diagnosis, I was committed to ensuring that my mother got the best possible treatment. This was the time my mother needed me the most and I was going to do my utmost to keep her in her own home with 24/7 care.

This was much easier thought than done, as an only child without a large extended family to share my responsibilities, the role of the main caregiver fell on me. My job as a surgeon meant irregular and long hours and as I worked exclusively in Government service, without a private practice, I did not have limitless financial resources.

Like many in Sri Lanka, I was faced with a lack of structured support, trained professional caregivers, and social welfare for patients living with dementia. My mother's case was further complicated as she had undergone a permanent colostomy during her battle with cancer and had a stoma bag in addition to a neuropathic leg which made her gait unsteady. Most caregivers have little or no training in the care required in such cases, especially with the added issues of dealing with the symptoms of dementia such as psychosis, delusions, etc.

I am fortunate that through my network in the medical fraternity, I have access to those who can provide this training but the rapid turnover in caregivers means this process is endless. There is simply no institution or organisation that offers these services, and it is up to the family to be 100% involved in the process of proper care, with little ability to step away or take a break from full-time supervision. Sri Lanka desperately needs infrastructure and social support that provides professional, customized advice on the care for each patient, which can be implemented within the financial means of the individual's family.

I try to give my mother as much social interaction as possible. I have found that social events are less stressful when I give others a 'heads up' on her situation and explain that she has a medical condition that makes her behave in a manner that is not 'herself'. It pains me that people see a very different person from the confident, caring professional she was and just consider her as 'insane'. I am well aware that many are compelled to keep their loved one confined to their home to avoid being mistreated or misunderstood in public which leads to even further social isolation and no break for the carer.

Since she started attending the activity centre managed by the Lanka Alzheimer's Foundation (LAFs), I found that my mother's interpersonal skills and use of her hands, be it to write, draw or handle implements; has increased significantly. Perhaps, because she meets different people outside her usual circle of family and caregivers, she is less introverted. When I tell her she is going to LAFS, there is a marked sense of anticipation and positive mood enhancement. The benefits have been immense and does much more for her than anything I or her caregivers can provide; once again reflecting that structured care and trained support can make a marked difference in both the lives of the patient and the caregivers.

This journey has not been without many personal sacrifices, my mother's illness and lack of specialised support has meant that my own career and personal life must take a back seat. It is impossible for me to be away for an extended period for additional training or exposure overseas both of which are critical to my progression in the field of surgery. But I have no regrets and I'm just grateful that I can be there for my mother who made me who I am today.

Even though I have many advantages due to my medical training and access to information and financial resources even if limited in the circumstances – I still often feel that I'm alone in my battle and that the help she gets is inadequate and far from what I would like to ideally provide her. I can't even imagine the plight of families who don't have even the basic knowledge or support and have to deal with so much social stigma as well, with little or no tools or coping skills.