

Looking after a person suffering from the disease can take its toll on the family, and the best way to deal with this is to strike a balance. On World Alzheimer's Day, **Kareena N Gianani** finds that while patients need more professional help, caregivers need emotional support too

**A**s soon as one enters the Kullarwar's home at Mahim, Vidya Kullarwar has to rush to be by the visitor's side. She isn't sure how Pratibha, her 78-year-old mother, who usually sits in their living room, will react to a stranger's presence. Soon enough, Pratibha enquires suspiciously and Kullarwar pacifies her, and firmly tells her that she might have to call the police if she doesn't calm down. Pratibha looks daggers at her daughter and shrugs, "Let them in — I must tell them I am being starved and beaten to death."

#### STRESSED AND GUILTY

Pratibha was diagnosed with Alzheimer's disease five years ago and Kullarwar assumed the role of her caregiver. Her one-bedroom flat accommodates five members with visible strain. But it is the emotional, physical and financial stress that Kullarwar is still struggling with. She admits that having the disease is nightmarish but also points out that the role of a caregiver is daunting. "I fear her safety, get frustrated at her demands, weep at her degeneration and yet, at the end of the day, wonder if it's all been worth it. I hate to admit it, but there are times when my fists curl up and I feel I just cannot take it anymore," says Kullarwar, glancing at her mother who sits oblivious, making clucking noises and muttering under her breath. The guilt that follows after that bout, adds Kullarwar, takes days to ebb.

As Alzheimer's associations observe World Alzheimer's Day today, related societies, doctors and caregivers feel that it is time that some focus shifts on caregivers too. At a high risk of burnout, most caregivers believe though Alzheimer's has turned their lives around, there is hardly anyone they can turn to for respite. "Your priorities shift overnight and nothing prepares you for it," says Kullarwar.

# Caring for Alzheimer's caregivers

Cynthia Pillai has learned to build her own support system while taking care of her mother Louiza who suffers from Alzheimer's —Vipin Pawar.DNA



## BALANCING THE ODDS

On some days, Pratibha gets violent and Kullarwar patiently obeys. On others, it is plain disobedience, sometimes with profanity. "It took me time to accept that my mother would never be her self. I realised that emotions will have to take a back seat."

Experts have always urged caregivers to set boundaries and be realistic — there are few rewards while caring for an Alzheimer's patient. Apart from the depression that affects almost 50 per cent of the caregivers, says psychologist Anjali Chhabria, the physical toll must also be kept at bay. Kullarwar, for instance, has developed hypertension in the last four years. "Caregivers tend to be too hard on themselves. They must strike a balance, vent out their emotions to a friend or partner and detach after a point," adds Dr Chhabria.

## OUTLOOK MATTERS

Cynthia Pillai says she is lucky to have reached that stage. Pillai sits in her Chembur home, upbeat and relaxed. Her mother, Louiza

Maheshwari is frail but there are no signs of strain on Pillai's face. "As her caregiver, I have learnt to reach out, build a support system and balance my work with my mother's needs. You can't shut yourself away; neither can you undermine the patient's loss of dignity. My mother fully understands her helplessness, she



just cannot express it, and that is what hurts me. This is Alzheimer's most overlooked effect," Pillai's mother regularly attends the day-care centre at Dignity Foundation, which Pillai sometimes visits to catch up with other members and see how they are faring.

It isn't because Pillai's mother didn't give her

## 'Old dementia patients have a duty to die'

One of Britain's experts on medical ethics has ignited controversy by recommending euthanasia for people suffering from dementia. Baroness Warnock, considered an intellectual giant though criticised for her extreme views on various subjects, said: "If you are demented, you are wasting people's lives, the family's lives and national health resources." — IANS

a tough time. "I've had my share of frustrations but when I started relating to my mother at her level, her responses improved." Pillai has never had to tie her mother's limbs (something many caregivers resort to) or lock her in a room to curtail movement. "There is always a way out. I gave her the right medication — not sleeping pills — and she was calmer." She says she treats her mother in the way she would want to be treated if she ever suffers from the condition in the future.

## HELP IS AT HAND

At the onset of the disease, it is a good idea to contact the local Alzheimer's and Related Disorders Society of India's chapter. They can counsel the family about the disease, what to expect as it worsens and ways to cope with most challenges. The body guides caregivers to 'memory clinics' closest to home, provides contacts of doctors and support groups. And as Pillai puts it: Alzheimer's throws up unexpected surprises and a caregiver must prepare him/herself for the patient's sake.

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