

Special Article – Family Caregivers

Stretching the End

Sheela Jaywant*

Goa, India

*Corresponding author: Sheela Jaywant, Goa, India

Received: June 14, 2018; Accepted: June 27, 2018;

Published: July 04, 2018

Short Communication

Mother's friend, Dr Y, treated her for a heart ailment for one year before she realized it might not be a cardiac problem at all. Mother's breathlessness was due to poor lung function, said the chest physician referred to. Asthma? COPD? What followed was years of coughing, keeping away from any breeze and the outdoors, and prescribed medicines. **Can misdiagnosis be avoided?**

She used to work, for two decades, around 11 hours a day with and for street-children. She attended music programs and talks on garbage management. She did *pranayam* and tried alternative therapies to alleviate her breathlessness. She took nutritional supplements recommended by an uncertified dietician. Many of these 'treatments' were against our (her daughters and their families') wishes, but maybe they worked, because she led an active life in spite of the respiratory handicap. I regret that we forced her to discontinue this 'placebo nonsense' towards the end, fearing that it might interfere with the stronger medications. She was convinced they helped the doctors' drugs to work better. **Her belief made her feel better, we took that away from her.**

There were two or three trips to the hospital in her seventies; nebulization was an SOS measure. In the monsoons, Mother left Goa, her home, to be with her grandsons in drier climes.

Once, when she was 83 yrs, she had stomach pain; the 'MD (Medicine)' she went to told her at her age nothing could be done for it. After nearly two months of suffering, a doctor in Mumbai told her it was a simple infection. A week-long course of antibiotics cured it. **'Old age-- discomfort is a part of it' is an attitude many doctors have.**

In Jan 2016, she had a spell of dizziness, 'nothing-to-worry' was the verdict. A couple of days later, she fell, slightly cracking her shoulder bone. Won't operate, said the ortho surgeon, she's too fragile. But don't worry, it will heal. Prescribed painkillers weren't consumed—her choice-- because they led to acidity. The medication for acidity didn't seem to help. It took three weeks for the crack to heal. There was pain, but Mother was keen on living till she was a hundred, and willed herself to first rest and then exercise as recommended. She was back to work within the month. **Having something valuable to do helps recovery.**

The two things that made Mother's life difficult were 1) sleeplessness at night and 2) severe pain in the knees. For the first, she was prescribed Restyl, which she refused to take because she thought it would make her brain sluggish. For the second, nothing worked. She had severe knee pain until the end. None of the doctors could figure it out, for she could walk without limping and the pain was

mostly at night. **Sad that she got no respite from that pain.**

After the 2016 fall, a doctor friend told me, 'max two years' was the thumb rule for a post-fall life-span. She continued to live alone, with a neurotic 24-hr companion. We met her as often as we could and she pampered us by cooking stuff we liked to eat. **Along the way, I took her for a talk on End of Life Care. No one answered her queries on 'Iccha-maran' or 'wish-for-death'. She read some articles about it. Death was always on her mind... paradoxically, how to delay/defer it.**

In early 2017, her blood-pressure, which was always high, wouldn't come down with her regular medicines. Her head pained. Dr Y changed her medicine and within the day, she felt 'confused and strange'. She phoned us in panic, at night. The 108-service in Goa is a boon, but **getting manpower to lift patient and stretcher is a problem.** We took her to a private hospital; the doctor assured us that the blood-pressure was under control and sent her home from Casualty. By morning, she was worse. Dr Y quickly changed the BP medicine over the phone and asked me to get done an emergency test for sodium-level. Fetching a technician home to collect blood took time. By then Mother was vomiting and losing consciousness. Dr Y came home hurriedly. "Rush her to hospital," she said.

"How long will I survive?" Mother asked her. "This is the end, I know it. Three days? Four?"

Her sodium-level was dangerously low because of the BP medicine consumed. **Geriatric dosages, geriatric practice, are tricky.** The first night in hospital, Mother was agitated and at one stage she pulled out the IV-line and bled. I requested that she be restrained until morning. My family was ok with this decision, but Dr Y said it was 'wrong' as we hadn't taken Mother's consent for it. I did it for her safety; Mother was in no condition to take a decision at that point of time. Subsequently, Mother had no memory of it.

Mother recovered from the event, and decided she could no longer live alone. Her move from a central flat in town where people came and visited, to my isolated house in a village, took its psychological toll on her. She was cut off from her work and her friends. The latter could not come easily to meet her: age and transportation issues. Her phone was her lifeline, but gradual deafness reduced its use. She missed human contact. However, she willed herself to walk, exercise, chant, read, participate in our activities as much as possible.

She kept track of her medicines, tests to be done, reports to be collected and doctor's visits. She wanted to consult with many doctors and we had to explain to her that only one doctor should monitor medicines as we wouldn't know interferences and contra-indications. **Responsible and aware patients reduce medication mistakes.** We had a woman employed to help with washing/bathing her. There are agents who 'supply' untrained maids. Ours had worked as a nurse's aide for 12 years and could give injections. **Careful selection of home-help is important.**

A September-2017 trip to Chennai was a bad idea. Although the

doctor had given a fit-to-fly letter, she was very ill. We wondered whether she'd make the return trip. Back in Goa, she was hospitalized almost immediately, again for low sodium-levels.

This time recovery was slow. Appetite for food and socializing was still good. She expressed her post-death wishes and made a will. The fact that her school might not be run the way she did after she was gone, broke her heart. None would love those children with the passion she did. She wanted to get well and continue with the work and she did every tiny thing the doctor recommended.

In December, she told the hospital-doctor during a visit that she was ready to die, but didn't want to suffer. What the end will be like, she asked. **"If you're not ready to suffer,"** he said, **"You are not ready to die."** (Truly, when the treatments stopped working, her breathlessness got worse and her body swelled up; it was only towards the very end that minute doses of morphine gave her relief. ***Wish we had given her morphine earlier, but availability and administration was an issue.***)

Through Feb-March 2018, she was in a Mumbai hospital. ICU. Test for TB. Bronchoscope done. Negative. Acquired UTI. Wrong-size catheter forced into urethra caused injury. Veins were punctured, clots formed. More pain. Request to shift her to ward was countered with "as soon as she stabilizes". Request for discharge brought this answer: "You'll be doing it against doctor's advice; what will you do when she gets breathless again?" ***The doctors convinced her she'd get better, so she agreed to stay on in the ICU.*** After shifting her to the ward, she wanted to go home. Every day she was told "tomorrow". Tests were continuously done. (Once, three electro-cardiograms were done in half a day, though she was told her heart was working fine. She asked: if the heart is fine, why are you continuing to do the tests?). She got fed up. She refused to eat/drink anything. She forced them to discharge her and told us never to take her to a hospital again. When asked directly, one doctor revealed to us that Mother wouldn't last more than six months. ***End of Life Care had begun in earnest.***

Getting a doctor home was difficult, especially in an emergency.

There was a portal which provided such services, but building a rapport with its doctors was not possible. Mother needed a familiar face. We got lucky, we traced some local doctors who were helpful. The first General Practitioner (GP) came and had a holistic chat with Mother and Mother was very comfortable with her. The pulmonologist spoke to all members of our family as well as Mother; medicines were reduced/modified to suit her. We kept a bi-pap, a nebulizer and an oxygen enhancer at home, with a respiratory technician on call. Came a time when none of these individually or together worked. We brought home some people she knew from a 'spiritual NGO'. Problems faced: first- few GPs in practice, second- those who visited did mostly planned visits, no emergencies, third- those who did emergencies were reluctant to sign death certificates.

We found ***no Hindu organization/person for end-of-life counseling.***

The 'ayah' (maid) employed through an agency was untrained but strong, able, pleasant and could handle Mother's unexplained shouting. My family comprises only senior citizens. This ayah was our rock.

Mother's appetite was ok, she was alert, but she refused to wear clothes or meet anyone and shouted at the caretakers. She was depressed, unable to walk on her own and the frustration showed. Her fingers, abdomen, feet began to swell. ***None of this was treated.*** Her anxiety was controlled with a patch. She insisted on signing a Living Will. Breathlessness worsened (Sunday night) and she was on bi-pap 24 hours a day, nebulizing seven times. We should have begun the morphine at this stage. A prescription was given on Wednesday. Procuring morphine was not difficult. She got two miniscule doses. Relief was prompt. Sadly, she passed away on early Friday morning, aware and conscious minutes before she expired.

Just before she passed away, she told my sister: "Just what I didn't want has happened to me. I'm now but a blob of flesh."