

For Those New to Caregiving

By Swapna Kishore

Fifteen years ago, my father collapsed while getting up from a chair. A few hours later, instead of editing a document I had to submit to a client, I was trying to figure out how to look after someone bed-ridden thanks to a hip fracture. I assumed then that the situation was temporary, but as days, weeks, and months went by, my life kept changing to accommodate caregiving--first for my father, who never quite recovered, and then for my mother, who has dementia.

My caregiving journey is dotted with successes and failures, days of fulfillment and days of frustration. I've been sharing my experiences through my blog and website, and in support group meetings. Some days ago, a friend asked me to jot down suggestions for people newly thrust into the role of caregiving. Here is what I think...

Most of us have very little idea of the intensity involved in extended caregiving. We may have looked after someone with a fever, or spent a week or so supporting someone recovering from a surgery, but that is quite different from caring for a person suffering from a serious or disabling condition such as late-stage cancer, cerebral palsy, dementia, or organ failure. We may not have imagined ourselves (given our gender/ qualification/ skills/ good luck) as persons who may need to provide such care.

The patient may be a loved one, or an acquaintance, or someone we have to care for because there is no one else to do so. The illness may be curable or one with a low chance of recovery, the duration may be a few months or may stretch across years. Whatever the case, this new responsibility may leave us feeling strange--uncertain, nervous, helpless, exhausted, sad, angry. And often, alone.

In this note, I am sharing things I wish I had known when I had just assumed the caregiving responsibility.

But before going any further, one important point: **we have to understand that caregiving is a role.** Caregiving will affect us in multiple ways. We need to understand what it involves and plan for it rather than assume and hope things will sort of fit in with what we are currently doing. Like many other roles we balance--as a professional, spouse, parent, child--the caregiving role has to be integrated into our life. In order to be effective caregivers, we must have a realistic idea of the time, energy and money this role involves, and balance it with our jobs and family, our hobbies, socializing, and sleep...

Over, now, to my suggestions for effective and less stressful caregiving. I will start by discussing the functional (planning and execution of caregiving activities) aspects and then move over to the emotional and other adjustments that can help us.

Understand the disease. We need to understand the basics of the disease and the treatment so that we can provide the necessary care and recognize and handle

emergencies. While we don't need to become doctors or nurses, we have to acquire skills relevant for our situation. It is important to understand the medications and their possible side-effects, symptoms to watch out for, and when to call the doctor. First aid knowledge can also be very useful. For bedridden patients, we need to learn home nursing (such as, how to change a soiled sheet or recognize and prevent pressure sores). We can consult support groups, other caregivers, and doctors to understand which topics are relevant, and to get the required information. And read books and watch training videos. While doctors are good resources, it is our responsibility to ask them the right questions and get any clarifications.

Set up systems for calling doctors and others to help. Patients may require frequent trips to various clinics and hospitals. We need to plan how to transport the patient, and also be ready for emergencies. For example, a first aid box at home is a must. We should have ready access to important phone numbers, such as the numbers of ambulance services, doctors who do home visits, home nursing agencies, chemists who deliver drugs at home, and relatives and friends we can contact when we face a problem. It helps to mentally run through scenarios of possible problems so as to decide what to plan for.

Understand what the patient wants, and how much the patient can be involved. In some diseases, patients remain alert enough to take decisions regarding their treatments and surgery. However, in many cases, the patient is not in a position to understand the options and make decisions. For example, the person could be suffering from advanced dementia, or could be in a coma. In such cases, caregivers have to make decisions on behalf of the patient. It always helps if we understand what the patient wants/ would have wanted. Open discussions can be held with the patient, if possible. We can also try to find out if the patient has communicated his/ her desires earlier.

Coordinate across multiple stakeholders. As caregivers who assume decision-making and responsibility, we may forget to involve other family members living at a distance, and this can lead to hurt and bitterness and disagreements. We must accept and remember that family members living in other cities/ countries may feel worried and concerned, and may want to be involved in caregiving. Also, caregiving gets overwhelming with time, and having the support and participation of others is useful. Others are more likely to be able to support us if we keep them informed and discuss our decisions with them (even though we may find it difficult and consider it a waste of time). We don't have to satisfy everyone or put up with criticism or blame-games--we can firmly put down any unproductive comments--but we should also not discard everything others say just because they are unable to participate in the day-to-day care.

Redesign life to include the caregiving role. Depending on the type and duration of the care required, we will need to make minor or major adjustments to free up enough time, energy, and money. Jobs may be shifted to flexi-time. Travel may be reduced and work-from-home packages opted for. We may have to move into the patient's home or schedule frequent visits. If the patient requires intense care and cannot be left alone, we may be confined to the house most of the time and therefore need to plan better for outside

activities like bank visits, ATM withdrawals, and shopping for groceries and vegetables. Socializing and vacations could become difficult.

Decide 'pacing' and see whether we need assistance: Often, anxious caregivers try to do too much, and then burn out and collapse. For example, we may try to sit near the patient and stay awake all the time, and soon be too sleep-backlogged to manage the care. It is impossible for any caregiver, howsoever well-intentioned, to provide intense care on a continuous basis. Every caregiving situation is characterized by the intensity of care required, type of care, and duration--we must understand this and set realistic goals and expectations. For patients with acute conditions, we may need to request others for help and employ home nurses. On the other hand, some patients do not require such heavy care, but the illness is a long-drawn one, likely to span months, even years. Caregiving such marathon-care cases at a sprint pace will result in burnout.

Recognize the emotional demands of caregiving. Most of us find it depressing and frustrating to care for someone who is severely ill, especially if the patient's condition gets progressively worse despite our efforts. We are emotionally affected if we love the patient because of our sense of helplessness and loss. Even if we are not emotionally attached to the patient, we get affected seeing the impact of the illness. Sometimes, we may have unresolved issues with the patient, and this creates resentment when we need to keep adjusting our lives to care for this person. The range of emotions caregiving induces varies from guilt and deep sorrow and fatigue to anger and frustration. We must understand that this is normal for caregivers, and not blame ourselves for these feelings.

Recognize that there will be bad days. On some days, caregiving is fulfilling because the patient shows improvement, or he/ she smiles at us and thanks us. On other days, the patient worsens, or is cranky and blames us or complains to others or gets agitated, and life seems just so pointless. We have been working very hard, and this discourages us. What we must remember is: a patient feeling worse on some days is not our fault; it is the nature of the disease.

Recognize that people may not understand/ appreciate our role: Sometimes others (those not providing care) do not understand our situation and may say something insensitive, or complain, criticize, or blame. Even close family members may make hurtful remarks because they feel neglected or suspect that we are overreacting to the situation/ exaggerating problems. That is not really surprising, because till we became caregivers, we, too, did not fully appreciate other caregivers. We should explain the situation calmly if we can, or excuse ourselves and walk away instead of exploding, because that always makes everyone feel worse. Making others assist us in some activities may also sensitize them to what caregiving is.

Use support groups and various facilities available: Caregivers, busy with fatiguing work, often get socially isolated and feel they have nothing in common with old friends. Support groups are very effective in reducing loneliness, as are online communities. We should also consider employing attendants and home nurses, availing day care facilities, or taking a vacation by using respite care. If balancing caregiving with our other roles

proves impossible, we can consider options like moving the patient to a long-term care facility or hospice. Counselors can discuss the pros and cons for such steps.

Nurture oneself. Fatigued caregivers often neglect their own health and well-being, and suffer from episodes of caregiver stress. But in order to take good care of the patient, we must remain healthy and cheerful ourselves. For this, we must take time to indulge in whatever relaxes us: walks, music, a good book, painting, maybe an outing with a friend. We must eat nutritious food and remain physically active. Yoga and meditation also contribute to health and well-being. Even so, some days are especially stressful, and we must recognize when we are feeling stressed so that we can call for help in time.

On a final note: As caregivers, we will face good days and bad.

Caring for someone may bring us heart-warming moments when the patient flashes a smile at us, or show that he/she knows that we care, or when friends and relatives appreciate our effort. These are memories we can cherish and use to tide over days which don't go that well.

When we are emotionally distressed by the caregiving work, or fatigued, or when we feel isolated, and when people around us ignore us, take us for granted, or criticize us instead of appreciating us --at such times, we can think of the fulfilling moments we have experienced. We can remind ourselves that caring for people is important. Definitely, we would like to be cared for when we need it, as will every person we know. We are multi-faceted persons performing a very necessary role, the role of caring, and we can appreciate ourselves even if others do not.