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Sr. Lilly Maria F.C.C., Chairman and President

From the Editors Desk

Editorial

This year has been very hard for many people. The economy is in bad shape with people losing their jobs, with the turnover of many businesses shrinking to half of what it used to be. We read of teachers selling vegetables, of desperate farmers marching to Delhi pleading for help. We seem to receive news regularly of the tragic death of dear ones, and the papers are full of acts of barbaric cruelty. And we wonder if this is the Kaliyuga told in the Hindu scriptures or the end of the world foretold in the Bible when “nation shall rise against nation, and kingdom against kingdom: and there shall be famines, and pestilences, and earthquakes, in diverse places.”

At the same time, almost every day there are extraordinary acts of kindness. Today I learnt about an organization called Lava Mae that has turned old buses into bathroom and shower stalls. They drive around offering their service free to the homeless,

along with towels, soaps, razors. There are others who go around giving free hair cuts and shaves. There are others distributing food. Treating the poorest of the poor with respect and giving them some dignity. Ordinary people doing extraordinary work, bringing miracles into people’s lives. It is heartening to note that Jeevodaya forced by Covid to close its doors, is now once more, with prayer and courage, receiving the terminally ill. The sick and dying can end the last months of their lives surrounded by care and love. It is fitting that this happens as Christmas approaches.

Christmas is a celebration of love and kindness, a message of peace, a symbol of radiant hope. You must not hate, hate is a disease, said one Holocaust survivor. Christmas is the triumph of love over hate. May miracles flow into your life, and may you be a source of miracles for others in the years to come.

A Merry and Blessed Christmas to all our readers.

Sr. Lalitha Teresa
Editor



CARE OF THE CARE GIVERS

...activities include planning, decision making, problem solving, accessing health system resources, and negotiating the health care system...

Dr. P.P. Bapsy
DM (Medical Oncology)

Cancer in a family causes disruption in many ways. The social and cultural background in India is very different from the west. Families in India are close knit, though times are changing and nuclear families are on the rise. Generally one of the family members becomes the care giver. If you're helping your family member or friend through cancer treatment, you are a caregiver. Caring for a person with cancer can be hard emotionally and physically. However, there can also be moments that are comforting and rewarding.

When you become a caregiver, you undergo a change in roles. Maybe you went from spouse to caregiver or from adult child to caregiver. Suddenly, you're a nurse, counselor and medical advocate in addition to being a wife, husband, daughter or son. Most of the time the caregiver may be the only person in the family who is working to support the family financially and this may lead to great stress. This article will focus on the responsibilities in brief, and tips to reduce the stress and have a better quality of life.

Role & responsibilities of the care giver:

A diagnosis of Cancer and treatment for the same has a great impact on the care giver. The patient's needs vary depending on the age of the patient, stage of the disease, type of treatment, and the general condition of the patient- whether they are mobile and can do the daily care activities or are bed ridden. Being a caregiver comes with its own set of challenges. It's a role for which most people feel unprepared. It takes time and understanding to adjust to the changes. While worrying about their loved one's health, caregivers are likely trying to balance the demands of their new responsibility with their personal obligations, such as family and work. A caregiver often wears many hats such as :

- **Medical advocate:** navigating the medical system, accompanying the patient to the hospital, and overseeing paperwork

- **Nurse:** taking care of the patient's physical needs
- **Counselor:** providing emotional support
- **Household manager:** dealing with meals, laundry, paying bills and caring for children
- **Wage earner:** working to maintain income and health insurance

Lists of activities will be endless. These include buying medication /dispensing; management of side effects; meals and nutritional assistance; supervision of treatments; adherence; errands/bill paying; emotional support; coordinating care; monitoring using electronic devices; and communication with providers.

Care activities include monitoring and interpreting symptoms and side effects and being watchful for emerging negative effects or adverse events from treatment. Supervision of medication administration and sometimes providing infusions or injections are common care activities for family members

Other direct care activities include wound care, external feedings, or ventilators. Care needs will vary depending on the setting- Like immediate post-operative, or chemotherapy and radiotherapy and care during terminal disease.

To provide this care, caregivers must have a number of complex skills and the ability to make care decisions. These activities include planning, decision making, problem solving, accessing health system resources, and negotiating the health care system. Along with this they have to handle their own emotions vis-à-vis the patient; emotions that come with attachment and the constant fear of losing a loved one.

- Patients may only feel comfortable with a spouse or partner taking care of them
- Caregivers with children struggle to take care of the parent too
- Patients may find it difficult to accept help from their adult children

"A diagnosis of Cancer and treatment for the same has a great impact on the care giver..."

- Balancing care giving with job responsibilities may be difficult
- Adult children may not want to rely on their parents for care
- Care givers may have health problems themselves – draining them physically and emotionally.

Tips for the care giver :

Learn more about Cancer Sometimes understanding cancer patient's medical situation can make one feel more confident and in control. For example, one should know more about the type and stage of cancer. It may help to know what to expect during treatment, such as the tests and procedures that will be done, as well as the side effects that will result during surgery, radiation or chemotherapy.

- **Find a cancer team you trust:** Find doctors who are experienced in your loved one's form of cancer and who work as a team to provide individualized care. An integrative approach is also important to help your loved one manage side effects during treatment. Doctors in the same location provide greater convenience and more streamlined care
- **Stay organized:** Keep a record of your loved one's medical history, test results, schedule of visits, Emergency numbers and a handy diary to make notes.
- **Ask for Help:** Take an honest look at what you can and can't do. What things do you need or want to do yourself? What tasks can you turn over or share with people? Be willing to let go of things that others can help you do like
 - Helping with chores, such as cooking, cleaning, shopping, etc
 - Taking care of the kids or picking them up from school or activities
 - Driving your loved one to appointments or picking up medicines
- **Avoid Burn out:** Caring for someone with cancer can be physically and emotionally draining. Physically, fatigue, changes in appetite or problems sleeping can cause weakness. Emotionally, one can become anxious, guilty, angry, frustrated or helpless.

Too often, caregivers put their own needs aside to focus on their loved one's needs. This may lead to caregiver burnout, which can express itself in as:

- Illness
- Depression
- Irritability
- Increased anxiety
- Social withdrawal
- Resentment

Ways to prevent burn out :

- **Stay up to date with your medical needs**

Keep up with your own checkups, screenings, and other appointments.

- **Watch for signs of depression or anxiety**

- **Take your medicine as prescribed**

- **Try to eat healthy meals**

Eating well will help you keep up your strength.

- **Get enough rest**

Listening to soft music or doing breathing exercises may help you fall asleep. Short naps can energize you if you aren't getting enough sleep.

- **Exercise**

Walking, swimming, running, or bike riding are only a few ways to get your body moving. Any kind of exercise (including working in the garden, cleaning, mowing, or going up stairs) can help you keep your body healthy. Yoga is very relaxing and stretching might help. Finding at least 15-30 min daily for these activities is a must.

Finally, How to Cope :

At times when you feel burdened or overwhelmed

- Focus on the value of caring – acknowledge that it is a demanding, difficult task that you have taken on and giving it the best, you can.
- Many find that this is a time when a spiritual connect is discovered and introspection helps in personal development
- Feel good about the new skills that you may be learning along the way – feeding, nursing. A lot of knowledge is gained with this experience
- Learn to enjoy the discipline, commitment, love, that this role brings with it.
- Many people look back on the period of caring and are filled with a sense of satisfaction that cannot be quantified.
- Set boundaries and limits - about what you are comfortable doing, what you can manage.
- It helps to prioritize and organize your time, keep a journal to note the good days and bad.
- Make time for yourself – socialize, exercise.

Over time, expect that relationships can change, especially with spouses, children. New roles and responsibilities will crop up as the disease progresses especially in advanced cancer.

Empathy is necessary along with a clear understanding of what will help the patient, especially when they start feeling annoyed or distressed at the loss of independence. Many times, you may think it selfish on your part to talk about your needs when the other's need or discomfort is much more but remember that you can provide better quality of care only if you take care of yourself.

With advancing disease, you will have to shift your mind set from maintaining hope to accepting palliative care., especially if it involves someone you deeply love.

Remember that through all this you need not be alone. A Support group for caregivers is a dependable shoulder for you to lean on and help you surf the choppy sea of caring.

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Dr. Bapsy, with her team conducts the 'Reboot your Life' supportive care program for cancer patients and caregivers to address unmet supportive care needs. She conducts on-line courses for patients and caregivers.

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Scan this QR code on your Smart Phone to view the Jeevodaya Anthem on YouTube

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