

Bhutan Cancer Society

Caregiver guidelines- *Love endures all things together.* 

What is a caregiver?

A caregiver is a person who takes care of chronic ill patients, without being paid for the work that they do, out of the unconditional love for their loved ones. Care giving to someone is another way of saying “I love you, I care for you and everything that I do is out of love”.

In most of the cases the caregiver are those who are close to patients such as spouses, siblings or the family relatives. As a caregiver you have so many roles to play: while taking care of patients, there are other things to take care of too! Times it’s weighing you down, seems tired and feels like why it hasn’t been well. Some caregivers have no option to give up on their daily task (even their job), if other family members are too busy.

What caregivers can do?

Supportive caregivers are a *source of strength for most of the patients; they motivate, encourage and walk together in courses of time.* Encouraging patients will boost their hope to live and battle cancer. Caregivers can be a very good channel to help patients cope up with the treatment and overcome the disease. A good caregiver can give positivity to the patient and add value and worth in their life. In other hands a low esteemed caregiver can affect the entire process of treatment and can be a barrier between a patient and the right treatment. A process of treatment starts right from the home environment and then adds on.

As a caregiver – other than being a *companion* for a patient – there might be things you may need to care for, such as dressing up, bathing or feeding the patient. As a caregiver you might have to look after your home chores, your office work, and your kids and still meet the needs of your patient.

A good caregiver is a vital healthcare resource. In many cases, the caregiver is the one person who knows everything that's going on with the patient. **Don't be afraid to ask questions and take notes on doctor's visits.** Learn who your medical experts are and have their contact for emergency requirements. You may have to keep track of your prescriptions, know which tests are to be done and medicine to be refilled.

At times taking care of normal day’s activities and arranging the scheduled visit with the patients to the hospital. This busy schedule could leave you with no time to take care of your own needs. You may also feel the need to turn down job opportunities, work fewer hours, or even retire early to meet the demands of being a caregiver. As a caregiver you could be in the situation of **taking a decision** for the treatment of your patients, and you would have to always remember to ask for consent from the patients, to be worried for the mistakes that might happen or that you might make. Sometimes you would be left with no clue of what’s going on, what does your patient actually want? You will wonder why he/she can’t do it by themselves at times you could feel like being caught up or trapped. There is always the possibility to improve how to handle things. As you are closer to patients, try to see things that they can do by themselves, like getting bath, going to the washroom, or taking medicine on time. Figuring out all these opportunities could make your work much easier. You, as a caregiver, can encourage patients to speak their mind and **reassure them of the fact** that they are not a burden for the family.

When patients are diagnosed with cancer they face a lot of challenges; as a caregiver you can help them fight these challenges. When a patient shares his/her challenges, always be open to listen, rather than sharing your ideas. As a caregiver, you may find yourself working closely with the cancer care team, doing things like:

- Giving drugs
- Managing side effects
- Reporting problem
- Trying to keep other family Members and friends informed of what's happening
- Helping to decide whether a treatment is working.

There are other day-to-day tasks you might do as a caregiver. Here are a few things you might help the patient with, or in some cases even do for him/her.

- Shop for and prepare food
- Eat
- Take medicines
- Bathe, groom and dress
- Use the bathroom
- Clean house and laundry
- Pay bills
- Find emotional support
- Get to and from appointments, test and treatments
- Manage medical problems at home
- Coordinate cancer care
- Decide when to seek health care or see a doctor for new problems.

All this work costs time and money. This could take a toll also on your health and well-being, but you may prefer to keep doing what “needs to be done” and suffer in silence. You may be glad to put the well-being of the patient with cancer above your own well-being. And your love for this person may give you the energy and drive you need to help them through this difficult time.

Some of the things you can do as a caregiver.

Good communication skills

Good communication with the person you are caring for is the most important part of your role. Some of the things that you can try to do to keep that patient involved.

- Help them live a normal life.
- Encourage them to share feelings, and support their efforts to share,
- Let your loved one know you're available, but don't press issues.
- Remember that people communicate in different ways.
- Take your cues from the person with cancer
- Respect the need to be alone. Sometimes, we all need time alone, even you.

You might find that the person you're caring for is acting differently –angry, quiet and withdrawn, or just sad. If you get the feeling that they aren't talking, make sure they know that you are always open to listening, even about the tough topics.

When can a caregiver ask for help?

To care for a person, and be a caregiver is always a challenge, as you might have to stay home to take care of your patients. It will cost you a lot of physical, emotional and social well-being. **To be optimistic** all the time is difficult, you might face social issues like financial issues, support from family or other social issues. Being a caregiver might be draining and you could be tired at times. As a caregiver you will need your space to sit back and gain some energy to move further. As you watch over your patient over a longer period of time you are likely to be distressed, in worries, in fear, hopelessness, guilt, confusion, doubt, anger, and helplessness, that can affect both the patient and caregiver (like witnessing your loved ones suffering from a disease.) As a caregiver you would always want to be productive for the patient, which

might make your mental, physical and emotional health be ignored.

Not taking care for your patient and taking time for you might make you feel guilty. However, being caregiver for 24 hrs, a month and for years could be a problem, and – as a caregiver – you should not forget that you have to be healthy physically, mentally, and emotionally to offer the best care possible for your patient. If you feel you need to talk to your family about your tiredness, then just do it. As a caregiver, always limit your expectations of patients. To be a caregiver is an overwhelming job, it will take away a lot from you.

Here are some things you can do to cope with your distress.

- Talk to your friends and family about the things you are feeling, go out for a walk or have lunch together.
- Do those that give you a sense of accomplishment. (Reflect on things how far you have come)
- Carry on the activities that would make you feel good or relaxed. (I.e. listening to music, writing or things you like.)
- Get to areas of building faith; get in touch with your spiritual leaders.
- Ask others to help you. (Human connections can help you stay strong, hold regular family meetings, make a list of things you need help for)
- Exercise, healthy diet, and get away from too much of tobacco use.

Here are something's not to do as you feel distress:

- *Drinking alcohol*
- Blaming yourself feeling you are not doing enough
- Stop expectations and accept the truth.
- Trying to do all things by you

Get professional help if you need it.

It is normal to be overwhelmed sometimes by caregivers ' responsibilities. However, if it becomes a constant problem, you may want to seek mental health professionals. Get professional help if you:

- If you feel depressed, physically sick, or hopeless,
- Feel like hurting yourself or hurting or yelling at the people you care for.
- Depend too heavily on alcohol or recreational drugs
- Fight with your spouse, children, stepchildren, or other family members and friends.
- Are no longer taking care of yourself.

Limitations as a caregiver:

As a caregiver you would always want to do your best and times we do things that are not in our control. Just know that you can't do everything by yourself and that it's okay to get help as a caregiver. Taking care of sick loved ones 24 hr is not an easy task and taking care of them for a longer period of time may be overwhelming and emotionally draining. As a caregiver you cannot always be optimistic, positive and hide your emotions of fear, hopelessness and worries. As a caregiver, you might become prone to be frustrated, especially when seeing that your loved one is not coping up for the treatment or not listening to you.

Some of the things you can't limit;

- Stop yourself from the fear of losing your loved one
- Being too overwhelmed
- Being in confused emotions or being frustrated
- Choice for treatment to be given to patients?
- Can't accept help when they are in pain.
- Make all family members will come to support you.

Know different kinds of treatment available for your patients.

- Surgery

Cancer surgery can be used in a lot of ways. Some of them are:

- ✓ To take out small piece of something that might be cancer to check it for cancer cells.(biopsy)
- ✓ To look into a body to see how much cancer has been spread.
- ✓ To take out cancers
- ✓ To take out most of the cancer to help other treatments like chemotherapy or radiation.
- ✓ To treat problems caused by the cancer, such as opening a bowel blocked by tumor.
- ✓ To put on devices like iv tube or feeding tube.
- ✓ To try to prevent a person from getting cancer, such as taking off women's breast.

When surgery is done, other treatment like chemotherapy and radiation will followed accordingly to the prognosis of the disease.

- chemotherapy

Chemotherapy is the use of strong drugs to treat cancer. What kinds of chemo is to be give is prescribed by your doctor. Chemo kills cells that grow fast, like cancer cells. It can also affect normal cells that grow fast too, but most of the cells can fix themselves afterwards.

Chemo may be used for:

- ✓ Keep the cancer from spreading.
- ✓ Make the cancer grow slower
- ✓ Kill cancer cells that may have spread to other parts of the body
- ✓ Make side effects from cancer better, like pain or blockages.
- ✓ Cure cancer.

- ✓ Chemo may be used to shrink tumors before surgery or radiation.
- ✓ Chemo can be used after or before surgery and radiations

Side effect of chemotherapy

Chemo drugs are very strong. They kill any cells that is growing in the body, this causes side effect in the body. When your patients are given scheduled time for the chemo, technical team would always advise you about all the side effects that may occur. There would be come post medication prescribed by medical staff, make a point of letting your patients take all the medicines. It will help patients treat symptoms of the side effect caused by chemo.

Some of the common side effect for chemo is as follows:

- ✓ Nausea and vomiting
- ✓ Hair loss
- ✓ Mouth and skin changes
- ✓ Fertility changes
- ✓ Constipations and diarrhea
- ✓ Fever
- ✓ Loss of appetite

- Radiations

Radiation therapy is the use of radiations to treat cancer and other problems. There are different types of radiations. Radiations are used in much more higher does to treat some cancer. Treatment with radiations can keep cancer cells from growing and spreading. Radiations can also affect normal cells but normal cells can repair themselves in course of time. Sometimes radiations only are used to treat cancer, other times they will be followed by surgery and chemotherapy.

Side effect of radiations

Some people have no side effects at all, while others do. Side effect depends on the part of body being treated.

Some of the radiations side effects are;

- ✓ Fatigue(feeling tired)
- ✓ Skin changes
- ✓ Eating problem
- ✓ Emotions changes due to change in appearance.

Some of the things to keep in mind:

- ✓ Have patients eat when they're hungry, even if it's not meal-time.
- ✓ Offer 5 to 6 small meals during the day rather than 2 to 3 large ones.
- ✓ Try to have them eat with family members.
- ✓ Keep healthy snacks close by.
- ✓ Complete post medications prescribed by the doctor
- ✓ Keep the patient in open space while cooking, don't serve hot meals.
- ✓ Rinse patients mouth with salt water if you see wounds appearing in their mouth.
- ✓ Walks around the house and some small exercise.
- ✓ Don't leave patient alone

There are services for cancer patients that you can avail contacting your Doctors and medical staff. Looking for social support from the community is always one of the ways to resist your distress. Some of the other services that you can avail for your patients are;

- Palliative care

Palliative care is a service availed to your patients to improve the quality of life. In this stage patients are provided services at home, with medical team visiting home and carrying all the activities that can improve the quality of

life for the patient. Some of the task that palliative care team carry out are

- ✓ Medicine refilling,
- ✓ Dr Consultations,
- ✓ minor wound healing
- ✓ Explaining about the disease prognosis.

At times caregivers and family member may need social support such as with financial burden, moral support, mental health assistance and other things, coping skills. In this regards, the **Bhutan cancer Society** would avail services according to need assessment.

Some of these services such as:

- ✓ Transportation services,
- ✓ counseling,
- ✓ monthly allowance/groceries,
- ✓ patient navigations
- ✓ Providing nutritional supplement.
- ✓ Home visit with palliative care
- ✓ Care giving counseling at oncology ward
- ✓ Advocacy on treatment at oncology ward.

All the services that had been provided are for smoothing the treatment flow and minimizing the burden for both patients and caregivers.