

# Cancer Association of South Africa (CANSA)



## Guidelines for Caregivers on How to Care for Themselves

### Introduction

A caregiver is anyone who provides physical, emotional, spiritual, financial, or logistical support and care to a loved one with a chronic, disabling or life-threatening illness, like cancer. A primary caregiver is the person who takes primary responsibility for someone who cannot fully take care of him or herself.



[Picture Credit: Caregiver]

A caregiver or *carer* is usually an unpaid person, and often a family member, who helps another individual with an impairment with his or her activities of daily living. Any person with a health impairment might use caregiving services to address their difficulties. Caregiving is most commonly used to address impairments related to old age, disability, disease or a mental disorder.

Typical duties of a caregiver might include taking care of someone who has a non-communicable or chronic illness or disease like cancer; managing medications or talking to doctors and nurses on someone's behalf; helping to bathe or dress someone who is frail or disabled; or taking care of household chores, meals, or bills for someone who cannot do these things alone.

With an increasingly aging population and an increase in the incidence of cancer in low- and middle income countries, the role of caregivers are being increasingly recognised as an important one, both functionally and economically.

The purpose of these guidelines is to provide information to caregivers of cancer survivors on how to take care of themselves.

(Cancer Support Community; Wikipedia).

## **Defining a Caregiver**

If someone is caring for a loved one or someone else who can no longer manage on his or her own, he or she is a caregiver. If someone helps a loved one or someone else with daily needs such as bathing or dressing, balancing the check book, or taking him or her to the doctor's office or the grocery store – he or she is a caregiver. A caregiver may be a son or a daughter, a husband or a wife, an in-law, a neighbour, a close friend or someone specifically recruited for the purpose. A caregiver may live in, or live next door, or across the town.

Someone who provides regular assistance to anyone is, therefore, a caregiver.

A caregiver needs as much information and support as the person with cancer does. After all, if a caregiver sacrifices his or her own health and well-being, they will not be at their best to effectively care for their loved one or the person for whom they are responsible.

With careful planning, good self-care and knowledge of available help, the responsibilities and job of a caregiver can be less stressful.

(Leukemia and Lymphoma Society; Merriam Webster; Jeannine Walston).

## **Guidelines on How Caregivers Should Take Care of Themselves**

Caregiving can have many rewards. For most caregivers, being there when a loved one or someone else who is in need, is a core value and something one wishes to provide.

During the course of caregiving, a shift in roles and emotions is almost certain. It is, therefore, natural to feel angry, frustrated, exhausted, alone or sad at times. Caregiver stress - the emotional and physical stress of caregiving - is common and caregivers need to guard themselves from this all the time.

Individuals who experience caregiver stress can be vulnerable to changes in their own health as a result.

Risk factors for caregiver stress include:

- Being female
- Having fewer years of formal education
- Living with the person one is caring for
- Social isolation
- Having depression
- Financial difficulties
- Higher number of hours spent caregiving
- Lack of coping skills and experiencing difficulty in solving problems
- Lack of choice in being a caregiver

Signs of caregiver stress - as a caregiver, one may be so focused on the person to be cared for that he or she does not realise that their own health and well-being are suffering. Caregivers must watch out for the following signs of caregiver stress:

- Feeling overwhelmed or constantly worried
- Feeling tired most of the time

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- Sleeping too much or too little
- Gaining or losing a lot of weight
- Becoming easily irritated or angry
- Losing interest in activities one used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain or other physical problems
- Abusing alcohol or drugs, including prescription medications

Too much stress, especially over a long time, can harm a person's health. As a caregiver, one is more likely to experience symptoms of depression or anxiety. In addition, one may not get enough sleep or physical activity, or eat a balanced diet - which all increases one's risk for medical problems, such as heart disease and diabetes.

The following are important:

Become informed - learn about the diagnosis and treatment of the person you are providing care for so you have a sense of what to expect. With the patient's permission, you may want to speak to the doctor or nurse if you have any concerns. They can recommend resources for learning more and getting support. Find out who else on the health care team (such as an oncology social worker, oncology nurse, or pharmacist) is available to you if you have any questions.

Keep up with one's own check-ups, screenings and medications - your health, as a caregiver, is very valuable. Stay on top of your doctor's appointments, and find a good system for remembering to take any medicines you need to take to stay healthy. Ensure that all your vaccinations are up to date. Make your own health a priority. But it is important to stay healthy so you can better care of your patient or loved one. Make sure to tell your doctor that you are a caregiver. Do not hesitate to mention any concerns or symptoms you may have.

Set personal health goals - for example, set a goal to find time to be physically active on most days of the week, or set a goal for getting a good night's sleep.

Do something good for oneself - take a few moments for yourself each day to do something enjoyable or relaxing, even if it is just taking a walk around the block. Give yourself credit for all you do as a caregiver, and find ways to reward yourself for your hard work.

Maintain a healthy diet - it is crucial to eat a healthy diet. Plan out the meals you intend to make at home a few days ahead of time. This will also help free up your schedule for caregiver responsibilities you did not anticipate.

[Picture Credit: Fruit and Vegetables]

Fruits, vegetables, lean protein, and whole grains are all essential nutrient dense foods. Nutrient dense foods are foods that contain protein, complex carbohydrates, healthy fat, vitamins, and minerals all needed by the body to function optimally. Consult a registered dietitian for specific




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recommendations based on your level of food tolerance.



No single food will supply all the nutrients your body needs, so good nutrition means eating a variety of foods. It is important to eat foods from each group at each meal every day.

[Picture Credit: Whole Grains]

Foods are divided into five main groups:

- Fruits and vegetables (oranges, apples, bananas, carrots, and spinach)
- Whole grains, cereals, and bread (wheat, rice, oats, bran and barley)
- Dairy products (milk, cheese, and yogurt)
- Meats and meat substitutes (fish, poultry, eggs, dried beans, and nuts)
- Fats and oils (oil, butter, and margarine)

[Picture Credit: Lean Meat and Meat Substitutes]



[Picture Credit: Dairy]



[Picture Credit: Fats and Oils]

It is important to eat foods from each food group at each meal every day. Meals and snacks should include starch/grains, protein, dairy, fruits, vegetables and fats. By eating foods from each food group at each meal, you will ensure that your body has a proper balance of all nutrients it needs to function. Eating meals and snacks at regular times is also necessary for controlling blood sugar levels.



Be sure to exercise - even just a 20-minute walk each day can help increase your energy levels and reduce your stress, and help alleviate feelings of depression and anxiety. All of these benefits will help with the stresses of caregiving. Walk, play sports, exercise, and/or practice another form of movement to keep your body in motion. Do not be stagnant. Movement generates profound energy within the body, mind, and spirit.



[Picture Credit: Exercise]

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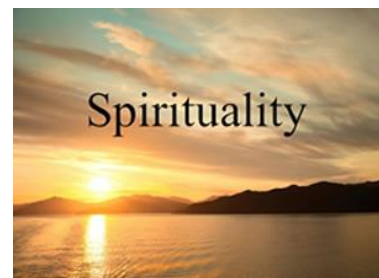
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Sleep well – it is recommended for adults to get seven to nine hours of sleep a day especially after a full day of caregiving. Even though this is not always possible for caregivers, setting a goal for how much sleep you want to get each day will help with fatigue in the long run. If you struggle to fall or stay asleep, you may want to talk to your doctor.

Take a break - if you are a full-time caregiver, you cannot always take a break when you feel like it. But learning techniques to de-stress throughout the day can be extremely helpful. Try closing your eyes for 5 or 10 minutes, listening to relaxing music, reading a book, taking a short walk round the house or calling a friend for a quick laugh.

Find meaning - with caregiving you may be struggling to understand why cancer has entered your life. Cancer may move caregivers to look at their own lives in a new way. You may find yourself reflecting on religion and spirituality, the purpose of life, and what you value most. Faith can be a source of strength and clarity. Educate yourself about navigating a world turned upside down and search for meaning through information regarding cancer as an existential crisis as well as meaning and purpose.



[Picture Credit: Spirituality]

Further defining one's beliefs - habits of mind are powerful constructs - our beliefs are the blueprint of who we are. Beliefs unconsciously drive our decisions, attitudes, feelings, coping patterns, life choices, and more. Evaluating your belief system is a tool toward healthier living, better clarity, and reducing stress. Defining beliefs helps caregivers better understand themselves, how they relate to other people, and life.

Accept help - it may be hard to imagine leaving a patient in someone else's care, but taking a break is one of the best things you can do for yourself as well as the person you're caring for. The emotional and physical demands involved with caregiving can strain even the most resilient person. That is why it is so important to take advantage of available help and support. Be prepared with a list of ways that others can help you, and let the helper choose what he or she would like to do. For instance, one person might be willing to take the person you care for on a walk a couple of times a week. Or someone else might offer to pick up groceries or even to cook for you.

Organise the help that is offered - decide which of your patient's needs you can or would like to take care of on your own, and which ones you need help with. Then, ask family members, friends, neighbours, co-workers or other caregivers to share the remaining care. Ideally, many people will want to help. Realistically, however, only one or two people may eventually be available. Still, these individuals can make a big difference in your load as caregiver. Check with community agencies, religious institutions, nearest office of the Cancer Association of South Africa (CANSA), or your hospital social worker for information on volunteer and respite care programmes.

Focus on what one is able to provide – do not give in to guilt. Feeling guilty is normal, but understand that no one is always a "perfect" caregiver. You are doing the best you can at any given time. The house does not have to be perfect all the time, and no one will care if you eat leftovers three days in a row. And you do not have to feel guilty about asking for help.

Join a support group for caregivers - support groups help many caregivers feel less alone. Support groups provide a safe, supportive environment for sharing feelings and discussing the challenges and rewards of being a caregiver. Group members provide a listening ear and share tips and resources they have learned along the way. A support group can be a great source for encouragement and advice from others in similar situations. It can also be a good place to make new friends.



[Picture Credit: Support Group]

If there is no support group for caregivers in your area, be the one to establish such a support group.

Seek social and other support - make an effort to stay emotionally connected with family and friends. Set aside time each week for socialising, even if it is just a walk with a friend. Whenever possible, make plans that get you out of the house. Many caregivers have identified that maintaining a strong support system is the key to managing the stress associated with caregiving. As a caregiver, you may sometimes feel overwhelmed and need more than friends or family members to talk to. Speaking with a counsellor or social worker can help you cope with some of the emotions or concerns you may be facing.

Forgive - an important act of self-love and support to others is forgiveness. Release thoughts that you have about the past or future. Ground yourself in the present moment and open yourself to new possibilities.

Anger - caregivers may be angry with themselves, their family members, or sometimes even the person with the health problem that they are caring for. Sometimes anger is associated with fear, panic, worry, resentment, and other emotions. Use anger to help motivate you into self-exploration, action, and constructive changes in your life.

Grief – if the patient you are caring for is your loved one, mourning the loss of that loved one's health and the life you had with one another before cancer may have occurred, is very natural. Give yourself permission to grieve these losses.

Guilt - guilt may include feeling like you are not helping enough, your work and any distance from your loved one is getting in the way, you are healthy in comparison, although dealing with complicated feelings. Identify and evaluate guilt and other associated emotions. Take control of them before they take control of your life.

Anxiety and depression - caregivers may feel anxiety and depression about how they are coping. This may be exacerbated by the impact of the illness on the patient, his/her family, as well as finances. Do not be afraid to acknowledge this – seek help.

Hope or hopelessness - hope and hopelessness may be felt to varying degrees. Hope is inspiration toward what may change over time such as cure, comfort, peace, acceptance, and joy. Hopelessness is related to anxiety, depression, and feeling out of control.

Loneliness - primary caregivers can feel alone in their role - even with people around them. Caregivers that feel isolated may perceive that others cannot understand what they are going through. Loneliness may also be related to less time for socialising and previous routines. To counteract this, you must consciously make contact with others around you to lessen the feeling of loneliness.

Stress - all of the feelings experienced as a caregiver, can be overwhelming and stressful. Caregivers may feel a loss of control. Stress is a response to any demand for change and how people respond to life. Learn about consequences and coping strategies of stress. Take control and conquer stress and its eventual negative influence.

(MD Anderson Cancer Center; Mayo Clinic; Cancer Care; Cancer Treatment Centers of America; Jeannine Walston; The Mesothelioma Cancer Alliance Blog).

### **How to Manage Being a Caregiver for a Member of the Family**

As primary caregiver for a patient that is a member of one's family, may influence the expectations that the rest of the family and even friends may have, for how one should care for the patient. This can sometimes cause conflict as family members may expect one to give up one's job, or hire more help. However, as primary caretaker, it is for the individual to evaluate and decide what kind of support he or she needs or does not need.

Many caregivers have expressed frustration as well as guilt when trying to care for a family member and handle all of the responsibilities of a household including the rest of the other family members. On the other hand, this overwhelming responsibility is often mixed with positive aspects of caregiving, such as the opportunity to experience greater closeness.

Knowing that friends and family will hopefully reach out to for information about the patient's condition and how the family is coping, may be sufficient reward to make one's tasks easier.

Sometimes, primary caregivers think the best strategy is to shield children from knowing about the disease of the family member. However, talking to children about the diagnosis and keeping them informed, in an age-appropriate manner, can help facilitate healthy coping and adjusting within the family.

If it is one's lifelong partner, it may be difficult to accept that the person one has loved for years is now different, perhaps forever. It is often tempting to tell one's partner that one misses the way things used to be, or ask the partner why he or she is different now, but the reality is that one's partner may not even realise the changes, making the situation even more complicated.

The best that one can do is to get the help and support one needs – both day-to-day support as well as emotional support – to be able to accept and live with the ‘new normal’.

In addition to everything one will be handling in one’s role as a caregiver, one may also find oneself taking on the responsibilities one’s spouse or partner used to handle. This can include everything from handling the family finances to taking care of young children and other dependents.

### **Intimacy**

The person one is caring for may be one’s husband, wife, or spouse. As one begins to live with one’s partner’s diagnosis, it is not unusual to start wondering about how it will affect one’s sexual life. Many people feel awkward or embarrassed to discuss this issue with their care team, but physicians, as well as other members of the care team, can help one find the answers to these questions.

The caregiver and his/her partner may have differing intimacy needs. Some people look to sexual experience as a way to reconnect, while others may not have the desire to open up physical or emotionally, particularly due to the exhaustion of being a caregiver. If one can, find ways to discuss the changes. Keep in mind that physical connection with one’s partner can be an excellent source of self-care for both.

*Intimacy is not always purely physical  
It is the act of connecting with someone so deeply – you can feel like you can see into their soul*

There may be missed signals. Often, partners look for small gestures and signals that lead to physical intimacy. Because of cognitive and mobility issues, these subtle communications may be absent and one may need to think of other ways to initiate contact.

One’s partner’s desire may change, whether because of cognitive changes or treatment, sexual function may be significantly affected. Some treatments may cause early menopause in women or impotence – sometimes temporary, sometimes permanent – in men. One may want to speak to a physician or a trained professional about these concerns.

As a caregiver, one can still be a romantic partner although the sexual relationship may change. Intimacy has many forms. Look for small ways to connect physically besides the touching that comes with caregiving. Take that time to connect emotionally as well by talking about things that will bring one closer together with one’s partner.

Do not hesitate to ask for help on behalf of self and one’s partner. There may be medical and emotional help available that can assist in regaining sexual intimacy. (American Brain Tumour Association).

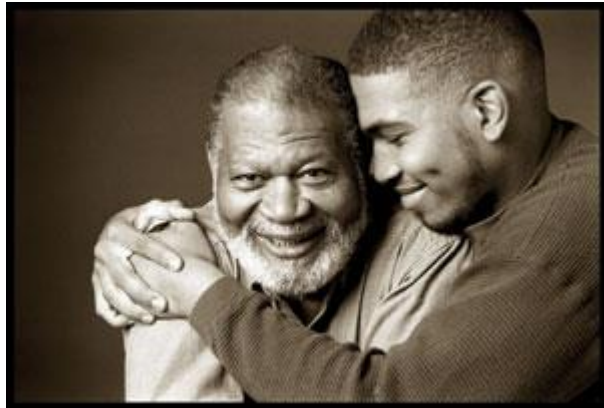
### **When the Patient is a Parent**

When one is an adult child of a parent, the role reversal may seem strange. Suddenly, one is caring for the person who was once the carer.



If nominated - willingly or not - to be the caregiver for an aging parent, dealing with the situation can be a challenge. It can be especially difficult if one's brothers and sisters are not willing to recognise their sibling responsibility.

[Picture Credit: Love your Parent]



While the responsibilities of caring for an aging parent might overshadow the benefits at times, it is important to remember the rewards of the situation as well.

For the parent, having a child around to spend time with, and provide care, may make a difference in quality of life.

There is little research on adult children caring for a loved one, but some of the findings on those caring for cancer patients are encouraging. Although caregivers often feel overwhelmed and anxious about their role, one study found that caring for a parent with cancer could have a positive effect on the well-being of the caregiver. Many adult children of cancer patients found emotional fulfilment in their role. Others were able to mitigate the stress of being a caregiver because of the support and satisfaction they received in their other roles as parent, spouse or co-worker.

Another study found that attitude had a large effect on the welfare of the caregiver. Adult children who felt a greater sense of duty for taking care of a parent had more depression. People with a more positive attitude about the caregiving experience – who voluntarily took on the role of primary caregiver, rather than feeling they had no choice – were happier. If one's sense of obligation to care for a parent is causing anger, resentment and symptoms of depression, it is best to seek out help, whether that means looking for home care options or asking for help from friends and family members. (WebMD; American Brain Tumour Association).



### **Warning: Caregiver Burnout – A Self-test**

To determine one's caregiver burnout index, answer the following 12 questions, add up the score (A = 4 points, B = 3 points, C = 2 points, and D = 1 point), and learn lifesaving strategies for managing the unique stress of caregiving.

How often do you get a good night's sleep (seven or more hours)?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often do you keep up with leisure activities that you enjoyed before caregiving?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often do you feel irritable or lose your temper with others?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often do you feel happy?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often do you find it difficult to concentrate?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often do you need more than two cups of coffee to make it through the day?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often do you lack the energy to cook, clean, and take care of everyday basics?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often do you feel hopeless about the future?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often are you able to relax without the use of alcohol or prescription sedatives?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

How often do you feel overwhelmed by all you have to do?

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

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**How often has someone criticised your caregiving or suggested you are burning out?**

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |

**How often do you feel that someone is looking after or caring for you?**

- |   |           |   |                 |
|---|-----------|---|-----------------|
| A | Every day | C | Sometimes       |
| B | Often     | D | Seldom or never |



What is the score?

This self-test is not a scientific or diagnostic measure; it is meant to help one identify whether one's stress level warrants taking steps toward better protecting oneself.

Add up your score. Each A = 4 points, B = 3 points, C = 2 points, D = 1 point.

**48-42: Keeping one's cool (low burnout risk)**

Your heart and head are both in the right place, and your stress-busting reservoirs are full, which helps you to give with grace and good humour. That said, caregiver stress often creeps up without a caregiver realizing it. Protecting your healthful habits is paramount.

*What to do:* Keep yourself well fuelled for caring by making time for yourself every day -- at minimum, aim for several five-minute pick-me-ups for caregiver stress. If you are in a relationship, know that a healthy marriage or other close relationship can be a source of strength; learn how caregiving couples can make it work.

**30-41: Feverish (elevated burnout risk)**

You are likely managing caregiver stress reasonably well but falling into a common caregiver trap: Letting yourself sink lower on the daily priority list than is healthy for you. Everyone has an occasional crazy-busy day, but too many of them results in chronic stress - which erodes well-being and places you at risk for depression, colds, and other illnesses.

*What to do:* Protect your time for self-care by learning seven ways to find more "me" time.

**18-29: Too hot to handle (high burnout risk)**

Your stress level is probably sky-high. You may already be experiencing symptoms of anxiety, depression, compromised immunity, and physical exhaustion that can lead to, or

complicate chronic diseases such as hypertension, diabetes, heart disease, and chronic depression. It is critical that you take steps immediately to lower your stress level, ideally through a combination of better self-care, a shared workload, and outlets for your complicated emotions, including talk therapy and support groups.

*What to do:* In addition to the suggestions in the sections above, look into respite care options – they are an important way to give yourself the break you need.

#### 12-17: Toast (already burned out)

It is a wonder - and a blessing - that you were able to find and take this quiz. You are running on empty, or is it more like barely running? Although you want to do your best for the person you are caring for, realise that your own health is at stake - and if you do not look out for Number One, you will not be able to help the person or persons in your care.

*What to do:* You need immediate help. Learn how to tell the difference between the normal stress of caregiving and depression and consult with someone you trust - a doctor, clergyperson, counsellor, or therapist, for counselling - and seek out medical assistance. At minimum, you need a physical check-up. You may also benefit from other therapies or from a break from caregiving that is as short-term as a vacation or as permanent as a relocation of the person in your care.

#### **Medical Disclaimer**

These Guidelines are intended to provide general information only and, as such, should not be considered as a substitute for advice, medically or otherwise, covering any specific situation. Users should seek appropriate advice before taking or refraining from taking any action in reliance on any information contained in these Guidelines. So far as permissible by law, the Cancer Association of South Africa (CANSA) does not accept any liability to any person (or his/her dependants/estate/heirs) relating to the use of any information contained in these Guidelines.

Whilst CANSA has taken every precaution in compiling these Guidelines, neither it, nor any contributor(s) to these Guidelines can be held responsible for any action (or the lack thereof) taken by any person or organisation wherever they shall be based, as a result, direct or otherwise, of information contained in, or accessed through, these Guidelines.

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