

Bliss  
COLLECTIVE



# CAREGIVER GUIDEBOOK

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# WHAT IS CANCER CAREGIVING?

Cancer caregiving is the act of providing daily care and support for your loved one who has cancer. Cancer caregiving is a critical contributing factor to your loved one's physical and emotional well-being.

## **WHO IS A CAREGIVER?**

A caregiver is a person who provides care and support to a loved one with a disabling or life-threatening illness such as breast cancer. The majority of caregivers are women, and the average age of a caregiver is 53 years old. Almost 90% of cancer caregivers provide care to a relative, and 60% provide care to someone who is 65 years or older. A cancer caregiver provides on average 33 hours of care per week to their loved one.

Generally, the primary caregiver is a spouse, partner, parent or .. Caregivers can also be close friends, colleagues or neighbors. Caregivers trustworthy and reliable. Caregivers have a huge influence on how your loved one deals with living with breast cancer – how well they stick to their treatment plan, how they are eating, and how well they are resting.





## HOW DOES IT FEEL TO BE A CAREGIVER?

Being a caregiver for your loved one with cancer typically means that you are handling all of the day-to-day demands of caring for them, and helping to make difficult decisions about their medical care and treatment. You may worry about their health, the uncertain future, financial limitations, and unexpected and unwanted lifestyle changes. You may experience feelings of fear, hopelessness, guilt, confusion, doubt, anger, and helplessness. You may feel like you are doing a great job of caregiver on some days, while on

other days you want to give up. This is all normal.

Like some caregivers, you may feel overwhelmed and unprepared to manage the responsibilities and feelings that go along with being in that role. You may even feel pressure from family, friends and the members of the cancer care team to provide care for your loved one, and this could feel quite stressful for you. It is important that you speak up and let your limits be known. If suitable, find someone to help you and/or arrange to have someone else be the primary caregiver.

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**YOU MAY EXPERIENCE FEELINGS OF FEAR, HOPELESSNESS, GUILT, CONFUSION, DOUBT, ANGER, AND HELPLESSNESS.**

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On the other hand, you may dive straight into the role, and feel empowered by a sense of personal satisfaction in caring for your loved one with cancer. You may see your role as caregiver as a meaningful role that gives you a chance to show your love and respect for the person. You may also feel good to be helpful and know that you are needed and appreciated by your loved one.

## TYPES OF CAREGIVERS

- **Primary caregivers** are commonly spouses, partners or who provide daily care for a loved one who is living with breast cancer. It is also common for the primary caregiver to be a paid attendant. Primary caregivers may live in the same household as the patient.
- **Secondary caregivers** typically provide back-up help to primary caregivers. These caregivers complete tasks so as to allow the primary caregiver time to recuperate or focus on their own personal business.
- **Working caregivers** help take care of their loved one, but maintain employment outside the home. In some cases, working caregivers are also primary or secondary caregivers.
- **Crisis caregivers** provide help in times when there is an emergency and the primary caregiver needs additional support.
- **Long distance caregivers** help with matters that can be coordinated remotely, such as arranging

repairs, paying bills, scheduling visits and researching healthcare options.

- **Community caregivers** live near your loved one who is ill and helps the primary caregiver by doing tasks such as keeping an eye on the house and delivering mail or taking care of the garden.
- **Future caregivers** step in to help as the breast cancer progresses.

## RANGE OF CAREGIVER RESPONSIBILITIES

As a caregiver, you may have a wide range of responsibilities. You may serve as a companion to your loved one. You may help feed, dress, and bathe them. You may arrange schedules, manage insurance issues, and provide or coordinate transportation. You may be a legal assistant, financial manager, and housekeeper. You may have to take on the duties of your loved one, and still meet the needs of other family members.

## CAREGIVING SOMEONE WITH A BREAST CANCER DIAGNOSIS

After the tests and biopsies, you and your loved one now know that she has breast cancer. This can be a very challenging time, but you should try to share your feelings and concerns with each other. This will help you feel a greater sense of connection and understanding.

As the two of you come to terms with the breast cancer diagnosis, as the caregiver, you'll likely be the one actively seeking information in pamphlets, books, and on the internet.



You may even call people who you think can help. As you gather information, you are becoming an informed and empowered caregiver. Keep in mind that breast cancer treatment is evolving and that not all information is credible. Take cues from your loved one and when they seem ready to hear about your research, speak with them.

In addition to learning about breast cancer, it is important to research which oncologist your loved one should have and where she should receive treatment. Your research should include looking for treatment options, it would be useful to meet with an oncology nurse or oncology social worker. Before the appointment, take the time to write down your questions. One important question is “what is the purpose of the treatment?” Is it to cure the disease, control or slow down the

tumor growth or provide comfort and relieve symptoms. You should discuss if clinical trials are an option, and what are the side effects of the treatment options. Make a strong partnership with the medical team. You will likely find that as your knowledge about breast cancer increases, you will begin to feel confident about the next steps.

## CAREGIVING DURING INITIAL TREATMENT OF BREAST CANCER

Now that treatment is underway, you may begin to feel a bit of relief that something is being done to help your loved one get better. Treatment might include surgery, radiation therapy, chemotherapy, and hormonal therapy. If you cannot attend all of their treatment appointments or doctor’s appointments, try to attend the first appointment of each type of treatment. That way, you’ll know what to expect.

## CAREGIVING DURING LONG-TERM SURVORSHIP OF BREAST CANCER

After treatment for breast cancer, the recovery phase can last for 6 months to 1 year or even longer. Be patient with your loved one. Continue to ask how they are doing and let them know that you are still available to assist them. You may need to continue doing the tasks that you did during treatment to allow your loved one time to re-immerse themselves into routines and regain their strength and energy. Consider joining a support group with your loved one to work through the emotional impact of cancer together.

As time progresses, you and your loved one will develop a "new normal" routine. However, unwelcome reminders may come up –your loved one developing a fever can trigger a cascade of fear and worry. You may find yourself once again unable to concentrate at work or feeling edgy until you receive news that all is well.

## CAREGIVING DURING BREAST CANCER RECURRENCE

Breast cancer may recur if the cancer is resistant to the treatment or if the treatment did not eliminate all of the cancer cells. The news of cancer recurrence can be more distressing than the first time but keep in mind that women live for years with metastatic breast cancer thanks to new treatment development. Also, since you have gone through this before, you are now equipped with the experience you need to adapt to the situation. Continue to work together with the medical team and be strong for your loved one.

## CAREGIVING FOR ADVANCED BREAST CANCER

As your loved one's illness progresses, it is important that you speak with them about their beliefs, values and wishes for end-of-life care. You should have this conversation before your loved one becomes debilitated, so that they can clearly express requests, make rational decisions and sign important documents.



You should speak with your loved one about life-sustaining treatments that are available, such as resuscitation, artificial nutrition, extended mechanical ventilators. Your loved one can also decide on which medical treatments they would like to undergo if the cancer becomes life-threatening. Similarly, you should ask your loved one to tell

you about their personal values and spiritual values related to death and dying, and you should help them prepare legal documentation such as a will or power of attorney for end-of-life preferences. You should also ask your loved one to identify whom they would like to make decisions on their behalf when they are unable to do so.

Speak with your loved one about how they would like to handle their personal business if they are unable to do so on this own. These personal business items include:

- **Birth Certificate** – Where is it? Note in which country they were born, in case you need to order a another copy.
- **Bank Accounts** – What are the account numbers? Who are the beneficiaries?
- **Investments** – What are the account numbers? Who are the beneficiaries?
- **Safe Deposit Boxes** – Where are the keys? Who are the beneficiaries?
- **Life Insurance Policies** – Where are they? Who are the beneficiaries?
- **Health Insurance Policies** – Where are they? Who are the beneficiaries?
- **Power of Attorney** – Who has been designated? Is the paperwork signed?
- **Will and/or Living trust** – Where are they?
- **Deeds/Property Titles** – Where are they? Who owns the property? Are there tenants?
- **Military Papers** – Where are the discharge papers?
- **Vehicle Registration** – Who owns the vehicle? Where is the certificate?
- **Income Tax Returns** – Where are they? Who is the accountant?
- **Funeral Instructions** – Is there a preferred funeral home? Any wishes for the process?

## CAREGIVING DURING BEREAVEMENT

When your loved one is at the point where medical treatments can no longer cure or control breast cancer, they may choose to focus on their comfort

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WHEN YOUR LOVED ONE IS AT THE POINT WHERE MEDICAL TREATMENTS CAN NO LONGER CURE OR CONTROL BREAST CANCER, THEY MAY CHOOSE TO FOCUS ON THEIR COMFORT.

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rather than continue burdensome and costly treatments that do not provide any benefit. As the caregiver, you may likely find yourself having a challenging and emotional discussion about palliative care with your loved one and their medical team – whether it is time for your loved one to receive palliative care and where to receive palliative care.

Palliative care is focused on medical treatment that helps your loved one maintain a quality of life with less suffering – treatment to relieve pain and manage symptoms such as nausea and fatigue. Hospice is where your loved one receives palliative care if their illness is expected to lead to death in less than six months. Hospice can be at a hospital, a nursing facility or even in the patient's home.

In anticipation of your loved one's end of life, you will continue doing the same activities as you were doing before, though it will probably be more

intense and stressful as their death becomes more imminent. Witnessing your loved one's deterioration in health, loss of independence and loss of life can be very traumatic. When your loved one has transitioned, you would have lost someone important to you, someone for whom you will grieve. You may feel out of place because you have lost one of the primary reasons for your existence. During this time, remember that grief is real. Give yourself permission to acknowledge, feel and express your sorrow. Similarly, keep in mind that grief does not follow a predictable path – it is unique to you. Believe in the future by caring for your spirit. Be gentle with yourself and find a meaningful way to mourn.

## CAREGIVING AT HOME

When caring for a loved one at home, you will find that some tasks are more routine while other tasks are more hands-on patient care.

### **Routine caregiving tasks at home**



**include:**

- Plan, prepare and serve meals; buy groceries; clean kitchen.
- Clean home, do laundry, remove garbage, maintain house and yard.
- Manage medical appointments; oversee finances, banking and bill payments; apply for financial assistance, social services; manage insurance coverage; attend to legal matters such as power of attorney.
- Drive or coordinate transportation

to appointments and other activities; acquire disabled parking placard from the Department of Motor Vehicles (DMV); maintain the loved one's car.

- Complete errands.
- Care for children, elderly family members, pets.

**Hands-on patient care tasks include:**

- Manage and administer medications
- Track treatments and side effects

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**MEDICAL CARE FOR YOUR LOVED ONE MAY INCLUDE THE HOSPITAL TEAM, A TEAM OF SPECIALISTS FOR INPATIENT AND OUTPATIENT CARE.**

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- Help with personal hygiene such as baths, oral care, skin and hair care; help with getting dressed.
- Carry/assist movement from one room to another or from bed to chair.
- Provide companionship; maintain safe and comfortable home.

### **CAREGIVING AT THE HOSPITAL**

When your loved one is visiting the doctor in a clinic or receiving care in a hospital, your critical role in their

records that are generated by various providers.

For hospital admissions, staff may call you to provide preliminary information and to let you know details regarding the hospital stay and answer any questions that you may have. While your loved one is in the hospital, try to be present when the doctor visits. The residents typically visit patients around 6:30 -7:30 a.m. and the attending physician may visit anytime from midday to the evening. Keep a list of questions to ask your loved one's

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## **YOU CAN CONSIDER HIRING SOMEONE TO VISIT THE HOME OF YOUR LOVED ONE TO HELP WITH HEALTH AND HOME CARE. FOR EXAMPLE, YOU MAY CHOOSE A COMPANION, A CERTIFIED NURSE, OR HOUSE CLEANER.**

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health care continues. Medical care for your loved one may include the hospital team, a team of specialists for inpatient and outpatient care. As the caregiver, you should feel comfortable asking the health care team important questions. You should also feel confident that they are spending sufficient time with you and your loved one during the visit, and that they are respectful of your loved one's health care needs. You should also feel empowered to advocate on behalf of your loved one – getting a second or third opinion as needed. You will need to be skilled at coordinating communication with the multidisciplinary medical team and managing medical

doctor and write down the answers. When your loved one is cleared to return home, discuss discharge plans with the health care team. Discharge plans may include physical therapy or nursing care.

### **HIRING HOME CARE SERVICES**

There are many professional agencies that offer home health aide services. You can consider hiring someone to visit the home of your loved one to help with health and home care. For example, you may choose a companion, a certified nurse, or house cleaner.

You may choose to find someone to help on your own – you advertise,



interview and hire someone privately, or you may choose to use an agency. If you choose to hire privately, you can set your hourly rate. Be sure that you are following employment laws so that payroll taxes and Workers' Comp insurance are covered. The disadvantages of hiring privately are that you may be on your own if the attendant is sick or does not show up. Also, you must conduct the interviews and background checks.

If you use an agency, the hourly rate will likely be higher than if you hired privately. The good news is that the agency will supply a replacement attendant as needed, the agency assumes employment responsibilities and they certify the attendants. To find an agency, you can search on the internet, request referrals for services from your doctor or social worker, ask friends and acquaintances for recommendations or call the patient services department at your hospital for a list of qualified agencies.

### **LONG DISTANCE CAREGIVING**

When you are far away from a loved one with cancer, there are several ways you can help. Before you do, it is a good idea to touch base with others who are local to help assess the situation and determine what you can do.

If you would like to visit your loved one, it is important that you carefully time your visit. For example, if they are having surgery, it might be a good idea to wait until after they have been discharged from the hospital. Or wait a few weeks later so that you can come at a suitable time that gives the local caregivers a chance to re-charge.

When you are offering your help, try to be specific and say things that you know you can follow through on. For example, you can ask "Are there phone calls you would like me to make?" From afar, you will be suited to be a listening ear to your loved one – sometimes it's nice for your loved one to know that you are "there" for



them and that they can share their hope, fear, optimism and despair with you. Also, from afar, you can help with decision-making, identifying helpful resources, and updating family and friends.

### **TAKING CARE OF YOURSELF AS A CAREGIVER**

As a caregiver, you may easily find yourself being caught up with all of the day-to-day demands of caring for

your loved one, and helping to make difficult decisions about their medical care and treatment. This could make you feel burned out. You need to focus on what matters so that you can strengthen your sense of purpose and meaning in your life. Taking care of yourself will allow you to better take care of your loved one. Here are some ways to take care of your own needs and feelings:

- **Set limits** – Being a caregiver every day, 24 hours a day, for months and years is difficult. Acknowledge to yourself that this is an overwhelming task and ask for help before stress build up. You can arrange for a respite caregiver or a sitter-companion that may be offered through local civic groups, religious groups or other community organizations. Health insurance may cover these costs.
- **Take a break** – Try to be away from your loved one for a bit of time every day, even if it is a short walk.
- **Infuse meaning into ordinary events** – Throughout the day, you will experience positive moments. It could be having someone hold the door for you, finding a rare parking spot, seeing a baby laugh. When such a moment happens, enjoy it and reflect on why it feels good. If you can, tell someone about it. These moments give you emotional time-off from anxiety and worry. It can help you de-stress and put you in an upbeat mood.

**Allow yourself to laugh** – Humor

is a great way to add perspective on life's difficult experiences. Don't feel guilty about your laughter. Laughter is known to be therapeutic. It can help you restore your energy and perspective.

## SPOUSES CARING FOR PATIENT WITH CANCER

Being a spouse of someone with breast cancer can be challenging. Like your loved one, you may feel anxious, helpless or afraid. You may even find that it is hard to take care of someone that you love. Most spouses experience high level of stress when their partner has been diagnosed with cancer, and this stress is evident before and after treatment. This stress can be brought on by trying to figure out how best to communicate and support each other, deal with new feelings, make decisions under the circumstances, juggle childcare, housekeep and work, adjust your social life, change your daily routine. You may also feel stressed about not connecting sexually with your loved one. Be understanding that your loved one's cancer and treatment may affect their sexual interest, sexual functioning and feelings of attractiveness.

Some interventions that you may be able to use to reduce your stress include talking to friends, praying, listening to music, reading a book, gardening, playing with a pet, exercising and taking a walk. Often times, the spouse may be concerned about leaving their loved one alone for a long period of time. In these cases, activities that can be done at home might be the most feasible. To help reduce your stress, speak openly with your loved one



about your emotional reactions and concerns and ask how they would like you to be involved. Support your loved one's true feelings, and support and validate their positive and negative sets of emotions.

If you feel highly anxious or depressed, you may need to see a physician or behavioral psychologist to learn stress management and relaxation techniques. You may also consider spiritual-based resources.

### **YOUNG ADULTS CARING FOR PARENT WITH CANCER**

If your parent has breast cancer and you are the caregiver, you may find it

making this transition smoothly is to communicate. Speak with your parents and siblings about what is expected and needed and ask for help.

### **YOUNG CHILDREN AS CO-SURVIVORS**

Children at almost any age can sense when something is wrong, and they will likely "know" when someone they are close to is not feeling well. While the illness may be difficult to explain to a child, it is better to discuss it with them than to avoid the topic altogether or acting as if life were normal. When children witness someone in the family with a serious illness, it can be scary for them, which can be emotion-

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difficult to balance your independence as an adult and helping your parent. It may even be a bit confusing because the roles have been reversed. Think of this as an opportunity to reconnect with your parent and care for them they way they cared for you. As a young adult, you be in school or in the early stages of your career. This is the time when your peers are focused on their careers and relationships. You may feel limited in your freedom to live like they are, and you may feel alone in managing your new responsibilities and emotions. The key to

ally stressful for them. The amount of information children want and need can be different for children even of the same age. Younger children often worry that they did something wrong that caused their loved one to comes ill. Here are some communication tips for discussing the illness with children:

- Use age-appropriate language to describe the illness and treatment to children. Let them know that cancer is not contagious and that no one will get sick as a result of spending time with the family

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## WHEN YOU ARE UPDATING THE CARE TEAM ABOUT YOUR LOVED ONE, GIVE THEM INFORMATION ON THE PATIENT'S OVERALL WELLBEING, PAIN, MEDICAL AND GENERAL CONDITION.

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member who is ill.

- Practice what you will say beforehand so that you know what words you will use and that you will be calm during the process.
- Don't be surprised when they offer their own explanations and insights about their loved one's illness. If they are worried that they may have done something to cause the illness, let them know that nobody can cause an illness to happen.
- Be honest and realistic when you speak with children. Let them know that some treatments are helpful, but that the family member may seem sicker.
- Allow children to help with caregiving. This could make them feel involved and good about being able to help their loved one.

### AS THE LEAD CAREGIVER, COMMUNICATING WITH FAMILY AND TELLING THEM WHAT YOU NEED

As the lead caregiver, you will be point person for communicating with the care team. Have each care member complete a sheet with their contact

information, availability on days and times and list of areas where they can help eg. meal planning, child care, etc.

When you are updating the care team about your loved one, give them information on the patient's overall wellbeing, pain, medical and general condition. Let the team know if the patient is eating and sleeping well, and if they are getting some kind of exercise. Let the team know if the patient is experiencing any pain, where the pain is and how the pain feels. Let the team know if the patient has been taking their medication on time and if they are complaining about side effects. You may also choose to update the team on whether the patient is mentally sharp and alert, and if there are any changes in their spiritual well being.

### CHALLENGES AND JOYS OF CAREGIVING

As a caregiver, it is important that you stay focused on what matters – taking the joys and challenges in strides will help you achieve this.

#### Some challenges of caregiving include:

- Being physically and emotionally stressed
- Having less time for your own



- personal and family life
- Managing your job and caregiving responsibilities
- Experiencing financial stress
- Having no privacy
- Feeling guilty that you are not doing enough

**Some rewarding parts of caregiving include:**

- Being as supportive as possible to your loved one
- Maintaining a good quality of life and well-being of your loved one
- Setting a positive example of respect and giving for others around you

### **TIPS FOR BEING A SUCCESSFUL CAREGIVER**

To be the best caregiver for your loved one, use these tips to adjust to the role.

- **Involve your loved one** – when your loved one has cancer, it may be difficult for them to take part in daily planning and decision making if they are feeling physically and emotionally drained by cancer and treatment. Ask them what they enjoy doing the most and help them to do so. Encourage them to share their feelings – listen and let them talk. Let them know you are available and that you enjoy being there for them, but let them decide when they need help. Remember to try different types of communication – sometimes writing a note or holding their hands can be a great way to communicate with each other. Take cues from your loved one. Sometimes they are ready to share or talk, and other times they

would like to remain quiet or be alone.

- **Prioritize your time and responsibilities** – to be an efficient caregiver, write down your priorities and organize them as urgent, important, both or neither. This way you can better focus on those tasks and projects that are necessary to maintain your home and life.
- **Explore your benefits** – to determine if you eligible for benefits that allow you to be a caregiver,

## WORKING TOGETHER AS CAREGIVERS

If you find that you need help to care for your loved one, you may find it difficult to ask for help because you think that this would be admitting that you cannot handle everything or you may be worrying that you will be imposing on others. Keep in mind that family members and friends often appreciate the opportunity to help you in these challenging times. Creating a care team will add support to your loved one and to you. Before you create a team, you should ask your loved

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## IF YOU FIND THAT YOU NEED HELP TO CARE FOR YOUR LOVED ONE, YOU MAY FIND IT DIFFICULT TO ASK FOR HELP BECAUSE YOU THINK THAT THIS WOULD BE ADMITTING THAT YOU CANNOT HANDLE EVERYTHING.

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check in with your employer to see if they provide paid or unpaid leave for family caregiving. Also, if your loved one qualifies as low income, you may be eligible to receive financial assistance for care, and you may be eligible to receive attendant care for your loved one through in-home support services.

- **Learn caregiving skills** – to develop your skills as a caregiver, you could sign up for workshops or classes that are offered either in person or online. These courses may be offered by social service agencies.

one if they would like to be involved. If yes, ask your loved one who they think would be an appropriate helper. Consider their skills, abilities to manage time and projects, strengths and weaknesses.

When the team is complete, coordinate everyone's efforts via a calendar. Provide an introduction to discuss issues regarding your loved one's illness, current needs, assigned roles, contact information, schedules, availabilities. Have a list of important information handy that covers medical information, doctor's contact information, location of pharmacies, grocery stores. Also, keep petty cash available



for helpers in case of emergencies and an extra set of house keys.

### **BEING A CAREGIVER WHILE KEEPING YOUR JOB**

Caregivers spend many hours each day caregiving for their loved one with cancer, while simultaneously maintaining a full-time job. Trying to balance work demands while taking care of loved one can affect your work life in several ways:

- You may become distracted or less productive
- You may get mood swings that confuse coworkers or make them reluctant to work with you
- You may need to call in sick or late
- You may need to forego retirement, especially if you are the sole provider

As a caregiver, if you are employed as a freelancer, consultant or entrepreneur, when you don't work, you do not get paid. If you have a more traditional job at a large company, your employer may offer benefits to help you take time off, exchange shifts, or allowing you to work remotely. If your company does not have these policies in place, you may still be able to make arrangements informally. The Family and Medical Leave Act (FMLA) guarantees up to 12 weeks off per year to take care of a serious ill family member (spouse, parent or child). Speak with your boss or benefits office about FMLA and other opportunities for a flexible schedule.

If you end up quitting your job, you will lose your source of income as well as your employer's health insurance coverage. For health insurance, you can use COBRA to pay for your own insurance. COBRA covers you for some months after you leave your job.

## HOW TO AVOID CAREGIVER BURNOUT

Caregiver burnout can manifest itself as illness, increased anxiety, depression, irritability, social withdrawal and resentment. To prevent any of these from happening to you, it is important that you know that it is ok to take time for yourself. Reach out to resources that offer support through counseling, support groups and other professional support services. Be open and honest when you need time off. Having a backup caregiver or a caregiver team will allow you to regroup and re-energize yourself when needed. Get enough rest, sleep, nutrition and exercise, and don't feel guilty about doing something healthy for yourself. Don't let your worries and stress eat away inside of you – talk to someone about your feelings and what worries you. Sometimes having someone to listen to you can make all the difference!

## SPIRITUAL SUPPORT FOR CAREGIVERS

Caring for a loved one whose health is failing is one of the most challenges and most sacred experiences you will have. Caregiving means selflessly tending to the needs of someone else for months or years. But as demanding as this experience might be, caregiving can also be rewarding. There are spiritual aspects of caregiving that make your experience meaningful.

To support you spiritually as a caregiver, speak with other caregivers to gain their insights, hear about their lessons of compassion and their journey through the various complicated aspects of caregiving. Read stories, poems and words of wisdom. Let these works inspire you and keep you centered throughout your caregiving journey. You can also call the Tigerlily Foundation 24/7 Prayer Line for confidential, non-denominational support at 1(888) 803-4680.



## CAREGIVER DISTRESS CHECKLIST

During your time a caregiver, you may experience levels of distress that vary from time to time. The checklist below contains items that you may be experiencing as a caregiver. Use it to identify what challenges you faced during the past week.

You are likely experiencing high level of distress if:

- a)** you answered "yes" to either or both questions 4 and 11, or
- b)** your total score for "yes" is 10 or more, or
- c)** your score on question 17 is 6 or higher, or
- d)** your score on question 18 is 6 or higher

If you are experiencing a high degree of distress, consider seeing a doctor for check-up. You may also ask for help with caregiving or consider joining a support group for caregivers (online and phone support are available).

### Caregiver Distress Checklist

1.	I had trouble keeping my mind on what I was doing.	<input type="checkbox"/> Yes <input type="checkbox"/> No
2.	I felt that I couldn't leave my loved one alone.	<input type="checkbox"/> Yes <input type="checkbox"/> No
3.	I had difficulty making decisions.	<input type="checkbox"/> Yes <input type="checkbox"/> No
4.	I felt completely overwhelmed.	<input type="checkbox"/> Yes <input type="checkbox"/> No
5.	I felt useful and needed.	<input type="checkbox"/> Yes <input type="checkbox"/> No
6.	I felt lonely.	<input type="checkbox"/> Yes <input type="checkbox"/> No
7 .	I felt upset that my loved one has changed so much from their former self.	<input type="checkbox"/> Yes <input type="checkbox"/> No
8.	I felt a loss of privacy and/or personal time.	<input type="checkbox"/> Yes <input type="checkbox"/> No
9.	I felt edgy or irritable.	<input type="checkbox"/> Yes <input type="checkbox"/> No
10.	I had sleep disturbed because of caring for my loved one.	<input type="checkbox"/> Yes <input type="checkbox"/> No
11.	I had crying spells.	<input type="checkbox"/> Yes <input type="checkbox"/> No

## Caregiver Distress Checklist

12.	I felt strained between work and family responsibilities.	<input type="checkbox"/> Yes <input type="checkbox"/> No
13.	I had back pain.	<input type="checkbox"/> Yes <input type="checkbox"/> No
14.	I felt ill (headaches, stomach problems, common cold).	<input type="checkbox"/> Yes <input type="checkbox"/> No
15.	I was satisfied with the support my family has given me.	<input type="checkbox"/> Yes <input type="checkbox"/> No
16.	I found my loved one's living situation to be inconvenient or a barrier to care.	<input type="checkbox"/> Yes <input type="checkbox"/> No
17.	On a scale of 1 (not stressful) to 10 (extremely stressful), rate your current level of stress. _____	<input type="checkbox"/> Yes <input type="checkbox"/> No
18.	On a scale of 1 (very healthy) to 10 (very ill), rate your current health compared to what it was this time last year. _____	<input type="checkbox"/> Yes <input type="checkbox"/> No

## COPING CHECKLIST FOR CAREGIVERS

As a caregiver, you will be busy caring for your loved one with cancer. You also need to take the time to care for yourself so that you can continue being a great source of support to your loved one. If your schedule is too crowded, identify someone you can ask for help or see what resources are available in your area.

## Coping Checklist for Caregivers

I have supportive family and friends around me.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I am doing a hobby or working on a project for work, church or my community.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I take part in a social or activity group more than once each month.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I am within 10 pounds of my ideal body weight for my height and bone structure.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I use relaxation methods such as meditation, yoga, or progressive muscle relaxation at least 5 times each week.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work

## Coping Checklist for Caregivers

I do something fun "just for me" at least 1 time during each week.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I get at least 150 minutes of moderate exercise each week (eg. walking or yoga) or 75 minutes of vigorous activity each week (such as jogging).	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I eat a well-balanced meal that is low in fat and high in vegetables, fruits and whole-grain foods 2 or 3 times in a day.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I have a place where I can go to relax or be by myself.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I set priorities and manage my time every day so that I can decide which tasks are important, see how much I can or can't do, and get the help I need.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I sleep 8 hours each day.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I am gentle with myself when things go wrong.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
My finances are in order.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I get regular check-ups by my doctors.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I take my medications on schedule.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I am not misusing alcohol or drugs.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I have attended religious services in the past and continue to do so.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work
I am in regular contact with other caregivers.	<input type="checkbox"/> All the time <input type="checkbox"/> Never <input type="checkbox"/> Needs Work

## WHAT NOT TO SAY TO CAREGIVERS

Knowing how tirelessly caregivers work, it is good to appreciate and encourage them. Often times, we don't know what to say, and we want to make sure that we do not say something that might hurt their feelings or somehow offend them. Below are some things that you should not say to a caregiver:

1. **Do not** comment on how tired they look or on their appearance. Rather, you should comment on the importance of what they are doing.
2. **Do not** say, "God doesn't give you more than you can handle." When you say this, if the caregiver is struggling, they may feel guilty and wonder whether they can, in fact, handle it.
3. **Don't ask** what you can do to support them. When you do so, the caregiver will have to think about some way for you to help. Instead, say what you are willing to do—make a meal, run to the grocery store, give them a day to have some time off.
4. **Do not** say their situation is "for the best." Since you do not know what is best, this is not appropriate to say. Instead, you can offer some practical help.
5. **Do not** say nothing. While silence can be golden, this is the time for you to ask the caregiver "How is your loved one doing?"
6. **Do not** say, "there is a blessing somewhere here." It is better to say, "How are you doing?" Then just listen.
7. **Do not** say, "I don't know how you do it." This implies that you think what they are doing is something awful and hard. Instead, let them know that you admire how courageous they are.
8. **Do not** say, "I know how you feel." You don't know how they feel because each situation is unique. Allow them to tell you how they feel.
9. **Do not** say, "This won't last forever." Those words can trigger grieving for the loss, and the loss will be painful whenever it comes.
10. **Do not** share your stories with them. They are handling all they can and sharing your stories will add unnecessary stress.



# AFFIRMATIONS FOR CAREGIVERS

*A loving Presence is with me,  
right here and right now.*

*I live in peace, happiness,  
and abundance.*

*All things before me are in divine order.  
I live from peaceful, unlimited joy within,  
expecting only the best.*

*God's perfect peace comforts  
and soothes me now.*

*I am always enfolded in divine love.  
I release any confusing thoughts  
and act in confidence.*

*The indwelling spirit of God  
powerfully guides me.*

# CAREGIVER BILL OF RIGHTS

**I have the right** to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.

**I have the right** to seek help from others even though my loved one may object. I know the limits of my own endurance and strength.

**I have the right** to maintain parts of my own life that do not include the person I care for just as if he was healthy. I know that I do everything that I reasonably can do for this person. I have the right to do some things just for myself.

**I have the right** to get angry, be depressed, and express difficult feelings once in a while.

**I have the right** to reject any attempt by my loved one to make me do things out of guilt or anger. (It doesn't matter if she knows they are doing it or not.)

**I have the right** to get considerations, affection, forgiveness, and acceptance for what I do for my loved one, as I offer these in return.

**I have the right** to take pride in what I'm doing. And I have the right to applaud the courage it has taken to meet the needs of my loved one.

**I have the right** to protect my individuality. I also have the right to a life that will sustain me when my loved one no longer needs my full-time help.

(Author unknown)

# RESOURCES

## **Tigerlily Foundation**

Tigerlily Foundation aims to educate, advocate for, empower and provide hands-on services and support to young women (15-45), before, during and after breast cancer. Our phone number is (888) 580-6253 and website is [www.tigerlilyfoundation.org](http://www.tigerlilyfoundation.org)

## **Unity**

Unity provides support to help individuals live a healthy, prosperous and meaningful life. Unity and Tigerlily Foundation have partnered to offer a personal, confidential and non-denominational prayer line that is accessible 24 hours a day. Call 1-800-NOW-PRAY (1-800-669-7729). You may also visit [silentunity.org](http://silentunity.org) to submit your prayer request online.

## **Family Caregiver Alliance**

The family Caregiver Alliance addresses the needs of families and friends providing long-term care at home through information, education, services, research and advocacy. For additional information, their phone number is (800) 445-8106 and their website is [www.caregiver.org](http://www.caregiver.org)

## **Cancer Legal Resource Center**

Cancer Legal Resource Center provides free and confidential information and resources on cancer-related legal issues to survivors, their families, friends, employers, health care professionals, and others coping with cancer. Their contact information is (866) THE-CLRC (843-2572) and [www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)

## **Family Medical Leave Act**

Family Medical Leave Act is a federal program that protects many caregivers and patients from job loss. The website is [www.dol.gov/esa/whd/fmla/](http://www.dol.gov/esa/whd/fmla/)

## **Care Pages**

CarePages websites are free blogs, created by patients and families that connect friends and family during a health challenge. The website is [www.carepages.com](http://www.carepages.com)

## **Caregiver.com**

Caregiver Media Group is a leading provider of information, support, and guidance for family and professional caregivers. The phone number is (800) 829-2734 and the website is <http://www.caregiver.com/>

## **Lotsa Helping Hands**

Provides a simple way for friends, family, colleagues, and neighbors to pitch in with meals delivery, rides, and other tasks necessary for life to run smoothly during a crisis. It uses a free, private group calendar, specifically designed for organizing helpers. The website is [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)



### **National Family Caregivers Association**

National Family Caregivers Association educates, supports, and empowers caregivers nationwide. Provides services to all caregivers independent of patient diagnoses, relationships and life stages, to help transform family caregivers' lives by removing barriers to well being. Their phone number is (800) 896-3650 and their website is <http://www.nfcacares.org>

### **Social Security Disability Insurance Program**

The Social Security Administration's disability insurance program pays benefits to disabled individuals (as determined by Social Security Disability Determination) and certain family members depending on Social Security taxes paid. For additional information, their phone number is (800) 772-1213 and their website is [www.ssa.gov/applyfordisability](http://www.ssa.gov/applyfordisability)

### **National Hospice and Palliative Care Organization**

National Hospice and Palliative Care organization is a national nonprofit membership organization that represents hospice and palliative care programs and professionals. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of enhancing quality of life for people dying and their loved ones. For additional information, their phone number is (800) 658-8898 and their website is <http://www.nhpco.org>

### **Hospice Education Institute**

Hospice ion Institute is an independent, not-for-profit organization, serving members of the public and health care professionals with information and education about the facets of caring for the dying and the bereaved. For additional information, the phone number is (800) 331-1620 and the website is <http://www.hospiceworld.org>



# NOTES



# NOTES *(continued)*



# NOTES *(continued)*





**Tigerlily**  
Foundation

*Beauty. Strength. Transformation.*

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