

(adapted from NCI Caregiver Booklet)

# Adjusting to Being a Caregiver

You've probably felt a range of feelings as you care for your furry love. These feelings can be quite strong and will likely come and go in strength as you go through his or her treatment. There is no right or wrong way to feel or react to these feelings. You may relate to all of the feelings below, or just a few. You may feel them at different times, with some days being better than others. One of the first steps to coping with feelings is to recognize that they exist and that having them is normal. Try to give yourself time to understand and work through your range of emotions.

**Anger.** It is common to be angry with yourself or other family members. Sometimes anger comes from feelings that are hard to show, such as fear, panic, or worry. If you can, try to avoid lashing out at others because of these emotions. Anger can be healthy if you handle it the right way. It can help motivate you to take action, find out more, or make positive changes in your life.

**Grief.** You may be mourning the loss of what you hold most dear--your beloved dog's health or the activities you shared with each other before cancer. It's important to give yourself permission to grieve these losses. It takes time to work through and accept all the changes that are occurring.

**Guilt.** Feeling guilty is a common reaction for caregivers. You may worry that you aren't helping enough, or that your work is getting in the way. You may feel guilty for not acting upbeat or cheerful. But know that it's okay. You have reasons to feel upset and hiding them may keep other people from understanding your needs.

**Anxiety and depression.** Anxiety means you have extra worry, you can't relax, you feel tense, or you have panic attacks. Many people worry about how to pay bills, how things will affect the family, and of course, how their dog is handling the illness. Depression is a persistent sadness that lasts more than two weeks. If any of these symptoms start affecting your ability to function normally, talk with your health care provider. Don't think that you need to tough it out without any help. It's likely that your symptoms can be eased during this hard time.

**Hope or hopelessness.** You may feel hope or hopelessness to different degrees throughout your dog's cancer treatment. And what you hope for may change over time. You may hope for a cure most of all. But you may also hope for other things, such as comfort, peace, acceptance, and joy. If you're not able to get rid of a feeling of hopelessness, talk to a trusted family member, friend, health provider, or spiritual or faith leader.

**Loneliness.** You can feel alone in your role as a caregiver, even if you have lots of people around you. You may feel that no one understands what you're going through. You may feel lonely because you have less time to see people and do things that you used to. Whatever your situation, you aren't alone. Other caregivers share your feelings.

## **OTHER WAYS TO COPE**

Let go of mistakes. You can't be perfect. No one is. The best we can do is to learn from our mistakes and move on. Continue to do the best you can. And try not to expect too much from yourself.

**Cry or express your feelings.** You don't have to be upbeat all the time or pretend to be cheerful. Give yourself time to cope with all the changes you are going through. It's okay to cry and show that you are sad or upset.

**Put your energy into the things that matter to you.** Focus on the things you feel are worth your time and energy. Let the other things go for now. For example, don't fold the clothes when you're tired. Go ahead and take time to rest.

**Forgive yourself.** This is one of the most important things you can do. Chances are that you are doing what you can at this moment. Each new moment and day gives you a new chance to try again.

# THINKING ABOUT YOUR STRENGTHS & LIMITS

One way that caregivers cope is to focus their energy on things they can control. This can mean learning more about cancer and treatment options. Some caregivers say that, looking back, they took on too much themselves. Or they wish they had asked for help with tasks sooner. Take an honest look at what you can and can't do. What things are you good at or need to do yourself? What tasks can you give to or share with others? Be willing to let go of things that aren't essential for you to do.

## SETTING YOUR PRIORITIES

Make a list of your weekly tasks and activities. Figure out how much time you spend on each one and how important it is. Scratch things off your to-do list if they aren't important. That will give you more time for the things you really want and need to do.

# WHY GETTING HELP IS IMPORTANT

Accepting help from other people isn't always easy. When tough things happen, many people tend to pull away. They think, "We can handle this on our own." But things can get harder as your dog progresses through treatment. You may need to change your schedule and take on new tasks.

Remember that getting help for yourself can also help your loved one because:

- You may stay healthier.
- Some of your helpers may offer time and skills that you don't have.

# HOW CAN OTHERS HELP YOU?

Would you find it helpful if someone made dinner for you or ran some of your errands? If so, you may benefit from having people help with tasks you don't have time to do. Your support system could include only one person or many people. And their support could take many forms.

People want to help, but many don't know what you need or how to offer it. It's okay for you to take the first step. Ask for what you need and for those things that would be most helpful to you. For example, you may want someone to:

- Help with household chores, including cooking, cleaning, shopping, yard work, and childcare or eldercare.
- Talk with you and listen to your feelings.
- Pick up a child from school or activities.
- Look up information that you need.
- Be the contact person and help keep others updated on your furry love's situation.

## WHO CAN HELP?

Think about people who can help you with tasks. Think of all the people and groups you know, including family, friends, neighbors, and coworkers. Members of your faith community, civic groups, and associations may also be able to help.

## BE PREPARED FOR SOME PEOPLE TO SAY NO

Some people may not be able to help. This may hurt your feelings or make you angry. It's especially hard coming from the people that you expected help from. You might wonder why someone wouldn't help you. There are a lot of reasons. Some common ones are:

- Some people may have their own problems to cope with, or a lack of time.
- Some people are afraid of cancer or may have already had a bad experience with cancer. They don't want to get involved and feel pain all over again.
- Some people believe it's best to keep a distance when people are struggling.
- Some people may not realize how hard things are for you. Or they may not understand that you need help unless you ask for it directly.
- Some people feel awkward because they don't know how to show they care.

If people choose not to help, you may want to explain your needs to them and be direct about what you are asking. Or you can just let it go. But if the relationship is important, you may want to tell the person how you feel. This can help prevent resentment or stress from building up. These feelings could hurt your relationship in the long run.

# Caring for Your Mind, Body, and Spirit

Roadblock	What Others Have Done
"Cancer is a private thing. I'd have to tell people about it to get any support."	<ul> <li>You can decide who to tell, what to tell them, and when and how. Some options are to:</li> <li>Tell only a few people close to you for now.</li> <li>Limit specifics about what you share. You can say, "He's sick," or "She isn't feeling well today."</li> <li>Ask another family member, friend, or member of your faith community to break the news.</li> <li>Get help from services or agencies in your area instead of from people you know.</li> </ul>
"Everyone has a lot going on. I don't want to bother them or put them out."	<ul> <li>If you are worried about being a burden to others, here are some things to think about:</li> <li>Many people probably want to help.</li> <li>If you let more people help, it can ease your workload.</li> <li>Would you want to help someone else in a similar situation?</li> <li>Would you mind if they asked you to lend a hand?</li> </ul>
"I can't explain it, but I just don't feel up to reaching out right now."	Many people don't want support when they need it most. You may often back away from your regular social life and from people in general. You may feel that it's just too much work to ask for help. Talk with someone you trust, such as a friend, member of the faith community, or counselor. This person can help you sort out your thoughts and feelings. They can also help you find ways to get support.
"I have a duty to take care of my family, myself."	Having a support system <i>is</i> a way of taking care of your family. Giving some tasks to others lets you focus on those that you feel you should do yourself.

## MAKE TIME FOR YOURSELF

You may feel that your needs aren't important right now. Or maybe by the time you've taken care of everything else, there's no time left for yourself. Or you may feel guilty that you can enjoy things while your beloved dog can't right now.

Most caregivers say they have those same feelings. But caring for your own needs, hopes, and desires is important to give you the strength to carry on. (See the Caregiver's Bill of Rights below.)

Taking time to recharge your mind, body, and spirit can help you be a better caregiver. You may want to think about:

- Finding nice things you can do for yourself, even just a few minutes can help
- Cutting back on different kinds of "for you" activities, rather than cutting them out
- Finding things others can do or arrange for you, such as appointments or errands
- Looking for new ways to connect with friends
- Finding larger chunks of "off-duty" time

# TAKE STOCK OF YOUR OWN FEELINGS

Giving yourself an outlet for your own thoughts and feelings is important. Think about what would help lift your spirits. Would talking with others help ease your load? Or would you rather have quiet time by yourself? Maybe you need both, depending on what's going on in your life. It's helpful for you and others to know what you need.

#### **FIND COMFORT**

Your mind needs a break from the demands of caregiving. Think about what gives you comfort or helps you relax. Caregivers say that even a few minutes a day without interruptions helps them to cope and focus.

Take 15-30 minutes each day to do something for yourself, no matter how small it is. (See Small Things I Can Do for Me".) For example, caregivers often find that they feel less tired and stressed after light exercise. Try to make time for taking a walk, going for a run, or doing gentle stretches.

You may find that it's hard to relax even when you have time for it. Some caregivers find it helpful to do exercises designed to help you relax, such as stretching or yoga. Other relaxing activities include taking deep breaths or just sitting still.

# **Small Things I Can Do for Me**

Each day, take some time to do something for yourself, no matter how small it is. This might include:

- Napping
- Exercising or yoga
- Keeping up with a hobby
- Taking a drive
- Seeing a movie
- Working in the yard
- Going shopping
- Catching up on phone calls, letters or e-mail

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## JOIN A SUPPORT GROUP

Support groups can meet in person, by phone, or over the Internet. They may help you gain new insights into what is happening, get ideas about how to cope, and help you know that you're not alone. In a support group, people may talk about their feelings, trade advice, and try to help others who are dealing with the same kinds of issues. Some people like to go and just listen. And others prefer not to join support groups at all. Some people aren't comfortable with this kind of sharing.

If you can't find a group in your area, try a support group on the Internet. Some caregivers say Web sites with support groups have helped them a lot.

# TALK TO A COUNSELOR

You may be feeling overwhelmed and feel like talking to someone outside your inner circle of support. Some caregivers find it helpful to talk to a counselor, psychologist or other mental health professional. Others also find it helpful to turn to a leader in their faith or spiritual community. All may be able to help you talk about things that you don't feel you can talk about with those around you. You also might find ways of expressing your feelings and learn ways of coping that you hadn't thought of before.

# CONNECT WITH YOUR LOVED ONE

Cancer may bring you and your dog together more than ever before. Often people become closer with their companion animals as they face challenges together. If you can, take time to share special moments with one another. Try to gain strength from all you are going through together, and what you have dealt with so far. This may help you move toward the future with a positive outlook and feelings of hope.

#### **CONNECT WITH OTHERS**

Studies show that connecting with people is very important to most caregivers. It's especially helpful when you feel overwhelmed. Try to find someone you can really open up to about your feelings or fears. You may find it helpful to talk with someone outside the situation. So many caregivers have an informal network of people to contact, either by phone or in person. And if you're concerned about a caregiving issue, you may want to talk with your dog's health care team. Knowledge often helps reduce fears.

## LOOK FOR THE POSITIVE

It can be hard finding positive moments when you're busy caregiving. It can be also hard to adjust to your role as a caregiver. Caregivers say that looking for the good things in life helps them feel better. Once a day, think about something that you found rewarding about caregiving, such as gratitude you've received, or extra support from a health care provider. You might also take a moment to feel good about anything else from the day that is positive, such as a nice sunset, a hug, or something funny that you heard or read.

#### LET YOURSELF LAUGH

It's okay to laugh, even when your furry love is in treatment. In fact, it's healthy. Laughter releases tension and makes you feel better. You can read humor columns, watch comedy shows, or talk with upbeat friends. Or just remember funny things that have happened to you in the past. Keeping your sense of humor in trying times is a good coping skill.

#### WRITE IN A JOURNAL

It can be a tricky balance between thinking too much about your dog's cancer and not thinking enough about it. But research shows that writing or journaling can help relieve negative thoughts and feelings. And it may actually help improve your own health. You can write about any topic. You might write about your most stressful experiences. Or you may want to express your deepest thoughts and feelings. You can also write about things that make you feel good, such as a stress-free day or a kind coworker.

#### **BE THANKFUL**

You may feel thankful that you can be there for your furry love. You may be glad for a chance to do something positive and give to another being in a way you never knew you could. Some caregivers feel that they've been given the chance to build or strengthen a relationship. This doesn't mean that caregiving is easy or stress-free. But finding meaning in caregiving can make it easier to manage.

If you can, try to keep doing some of your regular activities. Studies show that not doing those activities increases the stress you feel. Keep it simple and stick with things you do well. If you have to, change the time of day or the length of time you normally do things.

# LEARN MORE ABOUT CANCER

Sometimes understanding your dog's medical situation can make you feel more confident and in control. For example, you may want to know more about his or her stage of cancer. It may help you to know what to expect during treatment and what will need to be done.

# CARING FOR YOUR BODY

You may find yourself so busy and concerned about your dog that you don't pay attention to your own physical health. But it's very important that you take care of your health, too. Taking care of yourself will give you strength to help others.

New stresses and daily demands often add to any health problems caregivers already have. And if you are sick or injured, it's even more important that you take care of yourself, too. Here are some changes caregivers often have:

- Fatigue (feeling tired)
- Weaker immune system (poor ability to fight off illness)
- Sleep problems
- Slower healing of wounds
- Higher blood pressure
- Changes in appetite or weight
- Headaches
- Anxiety, depression, or other mood changes

# FINDING MEANING DURING CANCER

Many caregivers find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life, and what they value most. It is common to view the cancer experience both negatively and positively at the same time. You and your loved one may be struggling to understand why cancer has entered your lives. You may wonder why you have to endure such a trial in your life.

The way cancer affects one's faith or religion is different for everyone. Some turn away from their religion, while others turn toward it. It is common to question one's faith after cancer. But for others, seeking answers and searching for personal meaning helps them cope.

Many caregivers have found that their faith, religion, or sense of spirituality is a source of strength as they face life during cancer treatment. Many say that through their faith, they have been able to find meaning in their lives and make sense of the cancer experience. Faith or religion can also be a way for caregivers and their loved ones to connect to others in their community. These may be people who share similar experiences or outlooks, or who can provide support. Studies have also shown that for some, religion can be an important part of both coping with and recovering from cancer.

## Here are ways you may find comfort and meaning through your faith or religion:

- Reading materials that are uplifting and can help you connect to a higher power
- · Praying or meditating to help you feel less fearful or anxious
- Talking about your concerns or fears with a leader of your faith community
- Going to religious or spiritual gatherings to meet new people
- Talking to others at your place of worship who have had similar experiences
- Finding resources at a place of worship for people dealing with chronic illnesses like cancer

# Do You Need Help with Depression or Anxiety?

Many things listed below are normal, especially when you are dealing with a lot of stress. But if you have any of these signs for more than two weeks, let your health care provider know.

# **Changes in Your Feelings**

- Feelings of being worried, anxious, "blue," or depressed that don't go away
- Feeling guilty or worthless
- Feeling overwhelmed, out of control, or shaky
- Feeling helpless or hopeless
- Feeling grouchy and moody
- Crying a lot
- Thoughts of hurting or killing yourself
- Focusing on worries or problems
- Not being able to get a thought out of your mind
- Not being able to enjoy things anymore (such as food, being with friends, sex)
- Avoiding situations or things that you know are really harmless
- Having trouble concentrating or feeling scatterbrained, or feeling that you are "losing it"

# **Body Changes**

- Weight loss or weight gain without meaning to
- Trouble sleeping or needing more sleep
- Racing heartbeat
- Dry mouth
- Sweating a lot
- Upset stomach
- Diarrhea (loose, watery stools)
- Slowing down physically
- Fatigue that won't go away
- Headaches or other aches and pains

# TAKING CARE OF YOURSELF

These ideas for taking care of yourself may sound easy, but are a challenge for most. You'll need to pay attention to how you're feeling, in both body and mind. Even though you may be putting someone else's needs first, it's important to:

- Keep up with your own checkups, screenings, and other medical needs.
- Try to remember to take your medicines as prescribed. Ask your doctor to give you extra refills to save trips. Find out if your grocery store or pharmacy delivers.
- Try to eat healthy meals. Eating well will help you keep up your strength. If your loved one is in the hospital or has long doctor's appointments, bring easy-to-prepare food from home. For example, sandwiches, salads, or packaged foods and canned meats fit easily into a lunch container.
- 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. Be sure to talk with your doctor if lack of sleep becomes an
  ongoing problem.
- 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. Finding at least 15-30 minutes a day to exercise may make you feel better and help manage your
  stress.
- Make time for yourself to relax. You may choose to stretch, read, watch television, or talk on the phone.
   Whatever helps you unwind, you should take the time to do it. It's important to tend to your own needs and reduce your own stress levels.

# Talking with the Health Care Team

You will be asked to do many things during your loved one's treatment. One of your main roles may be to help your loved one work with the health care team. You may be asked to go to doctor visits, among other things. A few tips are listed below.

# HELPING TO GET READY FOR VISITS TO THE DOCTOR

- Keep a file or notebook of your dog's medical information. Include the dates of procedures and tests. Bring this file to doctor visits.
- Keep a list of names and doses of medicines and how often they are taken. Bring this list with you.
- Use only trusted sources if you do research for your dog, such as government and national organizations.
- Make a list of questions and concerns. List the most important questions first.
- Call ahead of time to make sure of the following:
  - The doctor has copies of all needed test results, records, and other paperwork.
  - You have directions, transportation, and if needed, hotel information.
- If you have a lot to talk about with the doctor, ask whether:
  - You can have a longer appointment (check on fees for this).
  - You can talk to the doctor by phone if there are further questions. Or perhaps others on staff can help you. For example, a nurse may be able to answer many of your questions.
- Talk with your partner (if applicable) before the visit to help prepare yourselves for the possibility that the information given could be different than what you both expect.

# TALKING WITH THE DOCTOR

- If you don't like how a question was answered, tell the doctor that you need him or her to explain more to help you understand.
- Talk with the doctor about any medical advice you find. Some advice may be false or misleading, or may conflict with what the doctor has told your loved one.
- If a concern is not being addressed, ask the question in a different way. This may help the doctor understand your concern better.
- Take notes or ask if you can tape-record the visit.
- Know that you have the right to change doctors if you feel your dog's needs aren't being addressed.

# **Questions To Ask About Treatment**

- What medical records, or copies, would you like us to bring?
- What can we do beforehand to prepare for treatment?
- How long will the treatment take?
- Can I or another family member be with my dog during the treatment?
- What can I do to help my dog feel more comfortable during the treatment?
- What are the side effects of the treatment?
- After treatment, what do we need to watch for? When should we call you?

# ASKING ABOUT PAIN

Although different side effects happen with cancer treatment, many caregivers say the one thing they hesitate to ask about is pain. Yet, dogs who have their pain managed are better able to enjoy life. If a dog is preoccupied by pain, you may notice personality changes. These might include not being able to sleep or not being able to partake in his or her normal daily activities.

The medical team should ask regularly about pain levels, but it's up to you to be open about any pain. Your dog does not have to be in pain or discomfort. Some people assume that there will always be severe pain with cancer treatment. This is not true. Pain can be managed throughout your dog's treatment. The key is to talk regularly with the health care team about pain and other symptoms. Drugs can also be adjusted or changed if they aren't working or are having unpleasant side effects. Don't be afraid to ask for stronger pain relievers or larger doses if you believe your dog needs them. Addiction is not an issue in dogs with cancer. Instead, drugs help them to stay as comfortable as possible.

#### SHOULD WE GET A SECOND OPINION

Some people worry that doctors will be offended if they ask for a second opinion. Usually the opposite is true. Most doctors welcome it. If you do get a second opinion, the doctor may agree with the first doctor's treatment plan. Or the second doctor may suggest another approach. Either way, you have more information and perhaps a greater sense of control. You then can feel more confident about the decisions you make, knowing that you've looked at your options.

#### REFLECTION

As a caregiver, you try to strike a balance each day. You have to care for your beloved dog while keeping up with the demands of family and work. Your focus tends to be on your dog's needs. But it's also up to you to try to stay in tune with yourself. Remember the things you need to maintain a healthy mind, body, and spirit. And if you can, try to find a quiet time for reflection each day. Meditating, praying, or just resting may help you keep a sense of peace at this time.

Whether good or bad, life-changing situations often give people the chance to grow, learn, and appreciate what's important to them. Many people who care for someone with cancer describe the experience as a personal journey. They say it has changed them forever. This is much like the way people with cancer describe their experience. It's not necessarily a journey that they would have chosen for themselves. But they can use their skills, strength, and talents to support their loved one while finding out more about themselves along the way.

# Caregiver's Bill of Rights

1. 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 furry one.

2. I have the right to seek help from others. 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 my furry love, just as I would if s/he were healthy. I know that I am doing everything that I reasonably can do, and therefore have the right to do some things just for myself.
 I have the right to get irritated, be glum, and express difficult feelings once in a while.

5. 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 beloved dog.

#### NO ONE KNOWS THE FUTURE

It's normal to want to know how long your furry love will have to live. It's also natural to want to prepare for what lies ahead. You may want to prepare emotionally too, as well as make certain arrangements and plans. But predicting how long your dog will live is not exact. The doctor has to take into account the type of cancer, treatment, past illnesses, and other factors. Your veterinarian may be able to give you an estimate. But keep in mind that it's a guess. Every patient is different.

Some dogs may live long past the time the veterinarian first predicted. Others live a shorter time. Also, an infection or other complication could happen and change things. While your veterinarian may know the situation best, he or she cannot know the answer for sure. In truth, none of us knows when we are going to die. Unexpected events happen every day. The best we can do is try, for ourselves and loved ones, to live fully and for today.