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# Caregiving for Your Loved One With Cancer

Presented by  
**Diane Blum, MSW**  
CancerCare

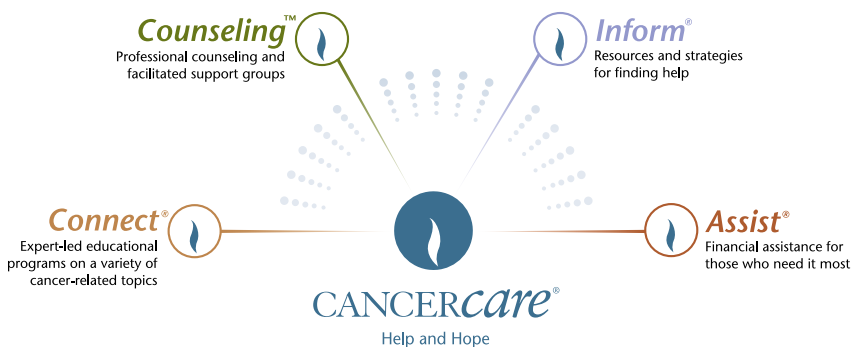
*Learn about:*

- Practical ways to help
- Taking care of yourself
- Coping tips
- Support for caregivers



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Help and Hope

## The *CANCERcare*® Constellation of Services



CancerCare's services are provided free of charge to anyone affected by cancer

1-800-813-HOPE (4673) • [www.cancercares.org](http://www.cancercares.org)

CancerCare is a national nonprofit organization that provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs—including counseling, education, financial assistance, and practical help—are provided by trained oncology social workers and are completely free of charge. Founded in 1944, CancerCare provided individual help to more than 97,000 people last year and received nearly 2.1 million visits to its websites. For more information, call 1-800-813-HOPE (4673) or visit [www.cancercares.org](http://www.cancercares.org).

### Contacting CancerCare

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#### Services

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If you are a health care professional interested in ordering free copies of this booklet for your patients, please use the online order form on our website, [www.cancercares.org](http://www.cancercares.org).

# Caregiving for Your Loved One With Cancer

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**Diane Blum, MSW**

Executive Director

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## INTRODUCTION

page 2

### THE ROLE OF THE CAREGIVER, *page 3*

- Helping To Manage Your Loved One's Treatment, *page 3*
- Providing Emotional Support, *page 5*
- Helping Your Loved One With Practical Matters, *page 7*
- Caregiving Under Difficult Circumstances, *page 9*

### TAKING CARE OF YOURSELF, *page 11*

- Staying Healthy, *page 11*
- Getting Emotional Support, *page 12*
- Getting Help With Your Caregiving Responsibilities, *page 15*

## GLOSSARY (definitions of blue boldfaced words in the text)

page 17

## RESOURCES

page 19

This booklet is made possible by a charitable contribution from Bristol-Myers Squibb.

# Caregiving can be a full-time job, but help is available for this very important role.

If you are helping to care for a loved one with cancer, you are a “caregiver.” You may not think of yourself as a caregiver. You may see what you’re doing as something natural: taking care of someone you love. Still, for many people, caregiving isn’t easy. But there are many things you can do to make it easier.



This booklet is designed to help you, the caregiver. It is filled with tips from professionally trained **oncology social workers** at CancerCare®, a national non-profit organization that has helped people with cancer and their caregivers for more than 60 years.

Read this booklet straight through, or refer to different sections as you need them. Some sections may not apply to your situation. Use this booklet in whatever way works best for you. Be sure to talk with your loved one often about what he or she feels would be most helpful.

Please note that important words and terms are highlighted in **blue**. Their meanings are found in the glossary at the end of this booklet.

## The Role of the Caregiver

Caregivers provide important and constant emotional and physical care for a person with cancer. Often, caregivers are family members or friends. They can live nearby or far away from the person they care for.

There are many different ways to be a caregiver. Caregiving can mean helping your loved one with day-to-day activities, like getting to the doctor or preparing meals. It can also mean helping the person cope with feelings that come up during this time.

*“Sometimes all it takes is a quiet moment together to know I’m making a big difference in helping my wife cope with her cancer diagnosis.”*

The kind of support that a caregiver provides will be different for each person. In general, caregiving tasks fall into three categories: medical, emotional, and practical. The following pages give many examples of things in each of these categories that caregivers can do to help.

### HELPING TO MANAGE YOUR LOVED ONE’S TREATMENT

Sometimes, a person diagnosed with cancer feels overwhelmed and may need someone to help him or her sort through treatment options. Or, he or she may want someone there to listen to the doctor’s instructions. Someone going through treatment might need a caregiver’s help in managing side effects or taking medication.

*Here are some ways to help manage your loved one’s treatment:*

- **Gather information.** Learn about your loved one’s diagnosis and possible treatment options. One good place to start is by asking the doctor or nurse what resources they recommend. There are also many reliable websites and cancer organizations that can provide accurate, up-to-date medical information.

# Some questions to ask the doctor

- What are the goals of this treatment?
- How long will the treatment last?
- Do you have any written information about this treatment?
- What are the side effects of this treatment?
- Are there any ways to help manage any side effects?
- How do we know if a side effect is severe enough to call you?
- Are there any other treatment options?
- Are there any **clinical trials** we should be aware of?
- What is the best way to let you know when we have questions about the treatment?



- **Go to medical appointments.** Before a visit with the doctor, write down any questions the two of you would like to ask. Bring a notebook or tape recorder so you can keep track of the doctor's answers and refer to them later.

Should you need to speak with the health care team without your loved one present, find out about the rules of the **Health Insurance Portability and Accountability Act (HIPAA)**. This law requires patients to sign consent forms before doctors can share information about their medical treatment.

- **Learn how to help with physical care.** Depending on how they are feeling, people going through cancer and treatment may need help with a wide range of activities they

would normally do themselves, such as bathing or dressing. Ask your loved one to let you know how he or she wants you to help with these tasks.

- **Ask about special instructions.** Check with the doctor or nurse to find out if there are any specific instructions you should be aware of. For example, are there any tips for managing a particular side effect, or does a special diet need to be followed during treatment? Keep the doctor's phone number in a place that is easy to find in case you have questions.

*“Before we go to one of her doctor’s appointments, my mom and I sit down and make a list of all the questions we want to ask.”*

- **Learn about organizations that help with medical care.** If you need help managing some of your loved one’s medical needs, ask your doctor or hospital social worker about local **home health agencies**. Under certain circumstances, these organizations can send a nurse to the home to help.

## PROVIDING EMOTIONAL SUPPORT

Going through cancer is often described as an emotional roller coaster, with many ups and downs. As a caregiver, you may see your loved one go through a wide range of emotions. While this can be difficult for both of you, your willingness to listen and offer support will make a difference.

It is hard to watch someone you care about go through so many difficult emotions. There are things you can do, however, to help both of you cope:

- **Listen.** It is important to listen without judging or “cheerleading.” We are often tempted to say “you will be fine” when we hear scary or sad thoughts. But simply listening to those feelings can be one of the most important contributions you make.

# Some common feelings experienced by people with cancer

- **Sadness.** Sadness can come and go during treatment. For some people, it can be more constant or last longer.
- **Anger.** For example, people can be angry about the way treatment and side effects make them feel, or about the changes their diagnosis has made in their lives.
- **Worry.** Cancer can be one of the most stressful events a person experiences. Common worries include fear of treatment not working, of cancer returning or spreading, and of possibly losing control over one's life and future. Other worries that existed before the cancer diagnosis, such as work or financial concerns, can add to the stress.



- **Do what works.** Think about how you've helped each other feel better during a difficult time in the past. Was a fun outing a helpful distraction? Or do the two of you prefer quiet times and conversation? Do whatever works for you both, and don't be afraid to try something new.
- **Support your loved one's treatment decisions.** While you may be in a position to share decision making, ultimately it is the other person's body and spirit that bear the impact of the cancer.
- **Get information about support groups.** Joining a support group gives your loved one a chance to talk with

others going through cancer and learn what they do to cope with difficult emotions. Ask a hospital social worker for a referral, or contact CancerCare®. We offer face-to-face, telephone, and online support groups for people with cancer.

- **If it's needed, continue your support when treatment is over.** This can be an emotional time for many people. Despite being relieved that the cancer is in remission, a person may feel scared that it will return. The end of treatment also means fewer meetings with the health care team on which the person may have relied for support.

*“Since my husband’s diagnosis, I keep a stack of funny movies that we can watch together. It really helps to lift both our moods.”*

- **Recommend an oncology social worker or counselor.** If you think your loved one may need additional support coping with his or her emotions during this time, suggest speaking with a professional who can help. Oncology social workers, like those at CancerCare, are specially trained to help people cope with the difficult feelings that often come up with cancer.

## HELPING YOUR LOVED ONE WITH PRACTICAL MATTERS

In addition to helping with medical and emotional concerns, caregivers often help by taking on many practical tasks. Some day-to-day activities caregivers can do include running errands, pitching in with household chores, preparing meals, and helping with childcare.

Because cancer can also place a tremendous strain on a family’s finances, caregivers are often left with the task of managing financial issues, too. Fortunately, there are many resources available to help.

# Keeping track of important papers

Many people find it helpful to keep all records or paperwork in one place. This will make things easier if you have questions or are trying to plan ahead. Important documents include:

- Copies of medical records
- Prescription information
- Income-related records
- Disability insurance
- Long-term care insurance
- Pensions
- Social Security
- Veterans benefits
- Bank statements
- Wills



*Here are some tips for finding financial help for costs related to cancer:*

- **Review your loved one's insurance policies** to understand what's covered. Your insurance company can assign a **case manager** to you who can explain what services and treatments the plan does and doesn't cover and answer any questions. He or she can also help explain any **out-of-plan benefits** the policy may offer.
- **Understand what your loved one is entitled to.** Some types of aid for people with cancer are required by law (these programs are called **entitlements**). A hospital or community social worker can direct you to the governmental agencies that oversee these programs.
- **Ask for help.** Should you need help with hospital bills, speak to a financial counselor in the hospital's business

office. He or she can help work out a monthly payment plan. If your loved one expects to run out of money, or has already, talk to his or her creditors. Many landlords, utilities, and mortgage companies are willing to work out a payment plan before a crisis develops.

*“Staying on top of bills reduces stress in our lives and allows me to be there for my husband when he needs it.”*

- **Apply for financial aid.** For many people, expensive cancer medicines pose a financial challenge. Fortunately, there are more than 475 programs that help those who qualify get medications for free or at a low cost. For more information, contact the Partnership for Prescription Assistance, listed among the resources on page 20. CancerCare® also provides financial help. We provide small grants for cancer-related costs such as transportation and child care. We also provide referrals to other organizations that can provide assistance. Call us at 1-800-813-HOPE (4673) to learn more.

## CAREGIVING UNDER DIFFICULT CIRCUMSTANCES

Even under the best of circumstances, caregiving is not easy. If your loved one with cancer lives far away, or if the two of you have a strained relationship, you may face additional stresses. This section offers tips for helping your loved one under these circumstances.

### *Long-Distance Caregiving*

Airplane travel, cell phones, and the Internet help family members who live far away from each other to stay connected. When someone you love gets cancer, the distance can seem hard to overcome.

*Here are some tips for coping with the challenges of being a long-distance caregiver:*

- **Focus on what you can do.** Feeling guilty for living far away from family or friends uses up energy. Instead, think

about all the ways you might be able to help. For example, can you schedule appointments or pay bills?

- **Make the most of your visits.** A visit when there is no medical emergency gives you time to set up a caregiving plan. Be sure to include some weekdays in your visit as some of the people you may need to meet with will not be available on the weekend.
- **When visiting, meet with some of your loved one's neighbors.** Ask if you can call them if you have trouble reaching your loved one by phone. They can reassure you if they have seen the person or can go by the house to check in.
- **Plan visits to coincide with medical appointments,** or schedule a meeting with the health care team. Your loved one will need to sign the HIPAA consent form to give his or her doctors permission to share medical information with you once you are back home.
- **Get support.** Ask family members and friends who live nearby to take on tasks you are not able to help with. Consider joining a support group to discuss your concerns with other caregivers. You can also speak with an oncology social worker or counselor who can help you come up with practical solutions to challenges you may be facing.

### ***When a Relationship Is Strained***

Caregiving for a person with whom you have had a strained relationship can be especially challenging. Old hurts, sad memories, and past misunderstandings can make caregiving more difficult.

Sometimes you and the person with cancer are able to put aside your differences and focus on the present. Working together to solve problems related to the cancer, rather than thinking about the issues you've had with each other, could help heal your relationship.

Sometimes, though, being in close contact with someone you've had conflicts with can cause distress. It is helpful if you can share your struggles with an oncology social worker or counselor or get involved in a support group. These resources can provide you with the specialized help, understanding, and comfort you need for your situation.

## Taking Care of Yourself

Taking care of a loved one can be a positive experience. For example, some people say that caregiving strengthened their relationship. But it can also be very stressful. Many caregivers say it often feels like a full-time job. Caregiving can be even more challenging if you have many other responsibilities, like working, raising children, or caring for your own health.

Sometimes, caregivers tend to put their own needs and feelings aside. It is important, though, for you to take good care of yourself. This will make the experience as positive as possible.

### STAYING HEALTHY

Caregivers spend a lot of time looking after the health of their loved one. This often means that the caregiver spends less time focusing on his or her own needs, such as eating well and exercising. Yet taking care of your own physical health is an important part of caregiving.

*Here are some tips for caring for your health:*

- **Stay active.** Experts recommend exercising for at least 30 minutes each day. Activities can include walking quickly,



jogging, or riding a bike. Keep in mind that you don't have to set aside a lot of time to exercise—you can work it into your day. For example, take the stairs instead of the elevator, or park your car farther away than you normally do.

- **Pay attention to what you're eating.** Keeping a balanced diet is an important part of taking care of yourself. Include fruits and vegetables in your meals. Nuts, yogurt, and peanut butter sandwiches are easy snacks with lots of protein that will keep your energy level up. Pack snacks if you know you will be with your loved one at the doctor's office or the hospital all day.

- **Get enough sleep.** Caregiving can be emotionally and physically draining. You may find yourself more tired than usual. Try to get enough sleep, and take naps when you need them.

- **Rest regularly.** As a caregiver, you may find that it is hard to relax, even if you have time for it. Deep breathing, meditating, or gentle stretching exercises can help reduce stress.

- **Keep up with your own check-ups, screenings, and medications.** Your health is very valuable. Stay on top of your doctor appointments, and have a system for remembering to take any medicines you need to stay healthy.



*“Along with managing my husband’s prescriptions, I make sure that I take my own medicines and visit my doctor regularly.”*

## GETTING EMOTIONAL SUPPORT

Caregiving is hard work that can affect your emotional well-being. Taking care of yourself includes coping with many of

## Some emotions the caregiver may feel

- **Guilt.** Sometimes caregivers feel guilty that they are healthy. Others can feel badly about enjoying things in life that their loved one cannot. It is also common for caregivers to feel that they are not doing enough to help.
- **Anger.** Caregivers may feel angry with the cancer itself, or with themselves, their loved one, family members, doctors, or others. Pinpointing the source of the anger can help you better manage the feeling.
- **Sadness.** It's natural to feel sad when someone you love is seriously ill. You might also miss the life the two of you had before cancer.
- **Worry.** At times, you may feel tense, nervous, or scared, or have difficulty relaxing. This is normal. Examples of things caregivers often worry about include their loved one's health, paying the bills, and how other family members are coping.
- **Discouragement.** Being a caregiver can sometimes feel like a long, bumpy road. It's easy to get discouraged from time to time. This is especially true if your loved one's treatment doesn't seem to be working, or if he or she gets better only to have the cancer come back.
- **Feeling overwhelmed.** It is common to feel overwhelmed as a caregiver. Providing medical, emotional, and practical support to someone with cancer can be a full-time job in addition to all your other responsibilities.

your own feelings that come up as you care for your loved one. Many people feel more emotional than usual when they are coping with a loved one's cancer. This is normal.

You cannot make difficult feelings go away, but there are things you can do to feel better.

*Here are some tips for coping with the emotional impact of your loved one's cancer:*

## Could it be depression?

It is normal to feel sad or angry when a loved one has cancer. But talk to your doctor if you have any of these feelings or symptoms for more than two weeks:

- Feeling overwhelmed or helpless
- Crying all the time
- Not being able to enjoy things
- Difficulty concentrating
- Trouble sleeping
- Upset stomach
- Weight loss or weight gain
- Thoughts of hurting yourself



These may be signs of depression, and help is available. Talk with your doctor to find the best treatment for you.

- **Take a break.** If possible, take some time out for yourself regularly. Even if it's just for a few minutes, doing something you enjoy can help you recharge. For example, listening to relaxing music or going for a walk might help you clear your head.
- **Be aware of your limits.** Remember that there are only so many hours in a day. Feel free to say "no" when people ask you to take on tasks you don't have the time or energy to complete. This way, you have time to do the most important things you need to do each day.
- **Keep a journal.** Writing sometimes helps people organize their thoughts and come up with practical solutions. Writing about your thoughts, feelings, and memories can also strengthen your spirit.
- **Open up to friends and family.** Ask friends or family members if they would be willing to be "on call" in times of stress. Or plan a regular "check in" time when you can get together or call each other.

- **Consider developing your spiritual side.** For some people, this means participating in religious activities. Others find spirituality in art or nature. No matter what your beliefs are, developing your spiritual side could provide comfort during this time.
- **Talk to a mental health professional about your feelings and worries.** Many caregivers feel overwhelmed and alone. You may need more than friends or family members to talk to. Speaking with a counselor or oncology social worker may help you cope with some of your feelings and worries. CancerCare®'s oncology social workers are just a phone call away.
- **Join a support group for caregivers.** Talking with other caregivers can also help you feel less alone. CancerCare offers free face-to-face, telephone, and online support groups for caregivers. These groups provide a safe haven where you can share your concerns and learn from others who are going through similar situations.
- **Go easy on yourself.** Sometimes, you might make a mistake or feel you could have done something better. Try not to be too hard on yourself. Focus on all the positive things you are doing for your loved one.

*“When I feel discouraged, I try to remind myself that I am learning as I go.”*

## GETTING HELP WITH YOUR CAREGIVING RESPONSIBILITIES

As a caregiver, it is important to know and accept your own limits. This is not a failure. Having a support system is part of taking care of your loved one and yourself. Decide which tasks you will do on your own, and which you will need help with. The following resources may be able to help you with your caregiving responsibilities.

*Here are some things you can do that will help you in your role as a caregiver:*

- **Check with family and friends.** Are there any family members, friends, members of your faith community, co-workers, neighbors, or others you can ask for assistance? Often people *want* to help. You just need to ask. Be specific about the kind of help you need, and keep records of who is handling what task. Certain websites can make it easier by providing calendars and other helpful tools for coordinating care.

*“I was surprised at how eager our friends were to help out. I wish I would have asked them sooner.”*

- **Learn about respite care programs.** Respite caregivers spend time with your loved one while you run errands or take some personal time. They may help with feeding, bathing, or daily routines. Ask for a referral from a health care professional, friend, or local service agency.
- **Know your rights.** If you work for a company with 50 or more employees and have worked there for at least one year, you are probably allowed unpaid leave under the **Family and Medical Leave Act** to provide care for your loved one. Many smaller companies allow their employees to use sick days and vacations for caregiving purposes. Ask your company’s human resources department for help.



- **Call CancerCare®.** Our professionally trained oncology social workers understand the unique challenges that caregivers face. We can work with you one-on-one to develop strategies for coping with whatever emotional or practical challenges you may go through. Contact us at 1-800-813-HOPE (4673) or visit our website, [www.cancercare.org](http://www.cancercare.org).

# Glossary

**case manager** A specialist who works for insurance or other types of agencies. Case managers help clients access the resources and services they need.

**clinical trials** Research studies that test new treatments, procedures, or ways of delivering medications. Clinical trials compare these new treatments to existing standard treatments.

**counselor** A licensed or professionally trained person whose advice on how to face problems and challenges often helps people feel more hopeful and in control.

**entitlements** Government programs that give financial and other aid to people who fall into specific groups—for example, “people with cancer.”

**Family and Medical Leave Act** A law that allows a person to take unpaid leave from his or her job if he or she is sick or needs to care for a sick family member.

**Health Insurance Portability and Accountability Act** A law that gives patients greater access to their own medical records and more control over how their health information is used.

**home health agencies** Organizations or agencies that provide medical and day-to-day care for patients living at home. Home care providers manage tasks such as giving medications, monitoring vital signs, assisting with a patient’s personal care (like bathing and dressing), and even cooking and cleaning.

**mental health professional** Someone who is trained to understand emotions, feelings, and behavior. A mental health professional can be a counselor, therapist, psychologist, psychiatrist, or social worker.

**oncology social workers** Trained professionals who work with people with cancer and their loved ones to help them cope with the emotional and practical challenges of cancer.

**out-of-plan benefits** Insurance coverage for medical services received from doctors who are not in your insurance network. Out-of-plan benefits differ from plan to plan.

**respite care** Short-term or temporary care for people who are ill. Respite care gives family and friends a break from caregiving.

**support groups** Groups where people can talk openly about their concerns, share information, and help each other cope. Support groups are sometimes led by professionals such as social workers or counselors.

# Resources

**T**his list includes only a few of the many organizations available to help you in your role as a caregiver. Call CancerCare®'s professionally trained oncology social work staff at 1-800-813-HOPE (4673) to find more resources to help with your particular situation.

## ■ CAREGIVING

### **CancerCare**

1-800-813-HOPE (4673)  
www.cancer.org

### **Family Caregiver Alliance**

1-800-445-8106  
www.caregiver.org

### **National Family Caregivers Association**

1-800-896-3650  
www.thefamilycaregiver.org

### **Well Spouse Association**

1-800-838-0879  
www.wellspouse.org

## ■ RELIABLE MEDICAL INFORMATION

### **American Cancer Society**

1-800-227-2345  
www.cancer.org

### **Cancer.Net**

(Patient information from the American Society of Clinical Oncology)  
www.cancer.net

### **National Cancer Institute**

Cancer Information Service  
1-800-422-6237  
www.cancer.gov

### **National Comprehensive Cancer Network**

Treatment Guidelines for Patients  
1-888-909-6226  
www.nccn.org

## ■ COUNSELING AND SUPPORT GROUPS

### **CancerCare**

1-800-813-HOPE (4673)

[www.cancercares.org](http://www.cancercares.org)

### **The Wellness Community**

1-888-793-9355

[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

## ■ FINANCIAL HELP

### **CancerCare**

1-800-813-HOPE (4673)

[www.cancercares.org](http://www.cancercares.org)

### **Partnership for Prescription Assistance**

1-888-477-2669

[www.pparx.org](http://www.pparx.org)

### **Patient Advocate Foundation**

1-800-532-5274

[www.patientadvocate.org](http://www.patientadvocate.org)

### **Social Security Administration**

1-800-772-1213

[www.ssa.gov](http://www.ssa.gov)

## ■ HOME CARE RESOURCES

### **National Association for Home Care and Hospice**

202-547-7424

[www.nahc.org](http://www.nahc.org)

### **U.S. Administration on Aging**

1-800-677-1116

[www.eldercare.gov](http://www.eldercare.gov)

## ■ END-OF-LIFE CARE

### **Hospice Foundation of America**

1-800-854-3402

[www.hospicefoundation.org](http://www.hospicefoundation.org)

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

1-800-658-8898

[www.nhpco.org](http://www.nhpco.org)



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The information presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

All people depicted in the photographs in this booklet are models and are used for illustrative purposes only.

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When one word changes your world,

**CANCERcare**<sup>®</sup>

makes all the difference



With CancerCare,  
the difference comes from:

- Professional oncology social workers
- Free counseling for you and your loved ones
- Education and practical help
- Up-to-date information

Our trusted team of professionally trained oncology social workers provides free counseling, education and practical help for you and your loved ones.



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