



## *Respite Care*

Respite care provides you a temporary break from your daily caregiving responsibilities. It is what we do best. Using respite services can support and strengthen your ability to continue taking care of your loved one with Alzheimer's, or any other issues in the home.

Remember, to effectively care for someone else, you need to take care of yourself first! If you are feeling stressed or overwhelmed, you will not have the patience needed to care for someone else appropriately.

We, as human beings, often think we can handle it alone or that we 'have' to handle it alone. You are not alone. You have your own needs and wants, and those should not be dropped out of the situation. And don't feel guilty about having your own needs and wants. After all, you are human, not "Super Caregiver". You are just you, and that is okay. An afternoon away can do wonders for you and your psyche. Gift yourself that time for yourself. You've earned it, and you need it.

Caregiving can mean helping with day-to-day activities such as doctor visits or preparing food. But it can also happen long-distance. You may have to coordinate care and services for your loved one by phone. Caregiving can also mean giving emotional and spiritual support. You may be helping your loved one cope and work through the many feelings that come up at this time. Talking, listening, and just being there are some of the most important things you can do.

Giving care and support during this challenging time isn't easy. The natural response of most caregivers is to put their own feelings and needs aside. They try to focus on the person with cancer and the many tasks of caregiving. This may be fine for a short time. But it can be hard to keep up for a long time. And it's not good for your health. If you don't take care of yourself, you won't be able to take care of others. It's important for everyone that you give care to you.

### Changing Roles

"Once a week, after I take the kids to school, I then take Mom to her doctor's appointment. Then I take her home and make her lunch and sit with her awhile. She argues with me every time because she wants to do it herself. It's hard for her to have to rely on me." - Lynn

Whether you're younger or older, you may find yourself in a new role as a caregiver. You may have been an active part of someone's life before cancer, but perhaps now the way you support that person is different. It may be in a way in which you haven't had much experience, or in a way that feels more intense than before. Even though caregiving may

feel new to you now, many say that they learn more as they go through their loved one's cancer experience. Common situations that many caregivers describe:

Your spouse or partner may feel comfortable with only you taking care of him.

Your parent may have a hard time accepting help from you (their adult child) since she's always been used to caring for you.

Your adult child with cancer may not want to rely on his parents for care.

You may have health problems yourself, making it hard physically and emotionally to take care of someone else.

Whatever your roles are now, accepting the changes may be tough. It's very common to feel confused and stressed at this time. If you can, try to share your feelings with others or a support group. Or you may choose to seek help from a counselor or psychologist. Many caregivers say that talking with a counselor helped them. They feel they were able to say things that they weren't able to say to their loved ones. See "Talking with Family and Friends" for more tips.

### Coping with Your Feelings

"It's emotionally exhausting, and I never know what to expect. One minute, things are looking up. Then a couple of hours later, something happens and I don't have the answers." - David

You've probably felt a range of feelings as you care for your loved one. These feelings can be quite strong and will likely come and go in strength as you go through treatment with the patient. Many caregivers describe this as "like a rollercoaster." You may feel sad, afraid, angry, and worried. 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. It may help to know that other caregivers have felt the same way that you do. 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.** Caregivers say that it's common to be angry with themselves, their family members, or the patient. 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. But if these feelings persist and you remain angry at those around you, talk with a counselor or other mental health professional.

**Grief.** You may be mourning the loss of what you hold most dear--your loved one's health or the life you had 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 or distance from your loved one is getting in the way. You may even feel guilty that you are healthy. Or 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 loved one is coping. 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.

"There is a helplessness that you feel. There are times when you don't know how to help. You can't take away the pain. You can't take away the frustration. All you can do is be there, and it's a very helpless feeling." - Cecile

Hope or hopelessness. You may feel hope or hopelessness to different degrees throughout your loved one'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. See "Connect with Your Loved One" for ways to connect with others.

### 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.

Understand anger. Your loved one may get angry with you. It's very common for people to direct their feelings at those who are closest. Try not to take it personally. Sometimes patients don't realize the effect their anger has on others. So it may help to share your feelings with them when they are calm. Try to remember that the anger isn't really about you.

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 and Limits

"Growing up, we were taught two rules. One is, 'Don't sweat the small stuff.' And second, 'Everything is small stuff.' And you have to decide what's important to you. Focus on what you can do, not what you can't." - Anne

One way that caregivers cope is to focus their energy on things they can control. This can mean:

- Helping schedule doctor visits
- Helping with day-to-day needs such as meals
- Taking on your loved one's tasks
- Learning more about treatment options
- Doing whatever else you can do

Many 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. This may mean disappointing someone else. But you need to take care of what's important to you, regardless of what others may think. Most people will understand if you tell them what is going on.

### Why Getting Help Is Important

"You have to learn that if people offer, let them do something. Ask for what you need to have done, because they don't know. You have to be willing to let go of your pride and let them help you." - Chevonne

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 the patient goes through treatment. You may need to change your schedule and take on new tasks. Many caregivers have said, "There's just too much on my plate."

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

You may stay healthier.

Your loved one may feel less guilty about all the things that you're doing.

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.

Drive your loved one to appointments.

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 loved one'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.

Finding Respite Help

Respite (RES-pit) helpers spend time with your loved one. They can be paid or volunteer their time. Many caregivers say they wish they had gotten respite help sooner. It can leave you free to rest, see friends, run errands, or do whatever you'd like to do. Respite caregivers can also help with physical demands, such as lifting the patient into a bed or a chair. If this service appeals to you, you may want to:

Talk with your loved one about having someone come into your home to help out from time to time.

Get referrals from friends, health care professionals, or your local agency on aging.

Ask respite helpers what types of tasks they do.

You can get respite help from family, friends, neighbors, coworkers, members of your religious or faith community, government agencies, or nonprofit groups. Whatever you do, remember that it isn't a failure on your part as a caregiver if you need some help and time to yourself.

### Be Prepared for Some People to Say No

"We've gotten lots of support, and some of it comes from people we expected it from. But a lot has come from those we don't know very well. And others we do know well have stayed away. You just never know with people." - Jessie

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.

### Roadblock What Others Have Done

"His cancer is a private thing. I'd have to tell people about it to get any support." You and your loved one can decide who to tell, what to tell them, and when and how. Some options are to:

Tell only a few people close to you for now.

Limit specifics about what you share. You can say, "He's sick," or "She isn't feeling well today."

Ask another family member, friend, or member of your faith community to break the news.

Get help from services or agencies in your area instead of from people you know.

"Everyone has a lot going on. I don't want to bother them or put them out." If you are worried about being a burden to others, here are some things to think about:

Many people probably want to help.

If you let more people help, it can ease your workload.

Would you want to help someone else who was in a similar situation? Would you mind if they asked you to lend a hand?

"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 is 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.

### Long-Distance Caring

"Our family is spread throughout the U.S., so it's hard to have a hands-on experience. But the phone calls have increased, with them calling to say, 'I love you, and what can I do to help?' Even though there isn't much they can do to help, just to have them call more has made it a little lighter load." - Patty

It can be really tough to be away from a loved one who has cancer. You may feel like you're a step behind in knowing what is happening with her care. Yet even if you live far away, it's possible for you to give support and be a problem-solver and care coordinator.

Caregivers who live more than an hour away from their loved ones most often rely on the telephone or e-mail as their communication link. But using these to assess someone's needs can be limiting. Aside from true medical emergencies, long-distance caregivers are faced with judging whether situations can be dealt with over the phone or require an in-person visit.

### Finding Contacts

Many long-distance caregivers say that it helps to try to create a support network of people who live near your loved one whom you could call day or night in a crisis or just to check in. You could also look into our Passionate Care program, adult day care centers, or meal delivery services in the area.

Having a copy of the local phone book for your loved one's area can also give you quick access to resources. Share a list of home, work, and cell phone numbers with the health care team and others in case of an emergency.

### Other Tips

Ask a local family member or friend to update you daily by e-mail. Or, consider creating a Web site to share news about your loved one's condition and needs.

Talk to electronic or computer experts to find out about other ways to connect with people. New advances using video and the Internet are being made every day.

Call a travel agent to find out if airlines or bus lines have special deals for patients or family members. The hospital social worker may also know of other resources, such as private pilots or companies that help people with cancer and their families.

If you are traveling to see your loved one, time your flights or drives so that you have time to rest when you return. Many long-distance caregivers say that they don't allow themselves enough time to rest after their visits.

Consider getting a phone card from a discount store to cut down on long-distance bills. Or, review your long-distance and cell phone plans. See if you can make any changes that would reduce your bills.

### 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 that your loved one 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.)

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

### Myths About Taking Care of Yourself\*

Myth: "Taking care of myself means that I have to be away from my loved one."

Fact: You can do things to take care of yourself with or without your loved one in the room with you. What is important is that you do not neglect yourself.

Myth: "Taking care of myself takes a lot of time away from other things."

Fact: Some self-care only takes a few minutes, such as reading an upbeat passage from a book. Other self-care can be done in bits and pieces between tasks.

Myth: "I'd have to learn how to focus on myself. I don't know if I can start."

Fact: Whenever things make you feel happier, lighter, more relaxed, or more energized, these count as taking care of yourself. Think of things that you already know work for you.

## Ways to Nurture Yourself\*

### Take Stock of Your Own Feelings

"I just need some quiet time. If my husband's taking a nap, I will read a book or sit on the porch because sometimes it's so intense. We have days where we go from chemo to radiation, and it can be very tiring." - Adele

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

You may find that it's hard to relax even when you have time for it. Some caregivers find it helpful to do exercises such as deep breathing or meditating.

Join a Support Group

"What I need at least once or twice a week is to talk to one person or a group of people that are in the same shoes as I am." - Vince

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 your loved one or others 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 loved one together more than ever before. Often people become closer 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

"It's okay for a neighbor to ask how I'm doing when they want the answer to be, 'I'm fine.' But when I'm really not fine, all I need is to talk to someone who can understand, or just hear me out. You don't have to have an answer, just listen to me." - Kathy

Studies show that connecting with people is very important to most caregivers. It's especially helpful when you feel overwhelmed or want to say things that you can't say to

your loved one. 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 loved one'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--a nice sunset, a hug, or something funny that you heard or read.

### Let Yourself Laugh

It's okay to laugh, even when your loved one 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 loved one'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 loved one. You may be glad for a chance to do something positive and give to another person 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 the Disease

Sometimes understanding your loved one's medical situation can make you feel more confident and in control. For example, you may want to know more about his stage of cancer. It may help you to know what to expect during treatment and what will need to be done. (See the Resources section.)

### Caring for Your Body

"When I get home from class, my mom and I take turns running while one of us stays with my dad. My run is my time for me, and the only way I can keep it together." - Meredith

You may find yourself so busy and concerned about your loved one 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?

As mentioned earlier, many of the things listed below are normal. This is especially true 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. He or she may have ideas for treatment.

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
- 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 they are a challenge for most caregivers. 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

### Helping to Get Ready for Visits to the Doctor

### Talking with the Doctor

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 the patient'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 loved one, 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 and the patient 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 loved one 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 your loved one takes you with him to talk with the doctor, here are some tips:

If you don't like how a question was answered, tell the doctor that you need 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 your loved one has the right to change doctors if he feels his needs aren't being addressed.

### Questions To Ask About Treatment

What medical records, or copies, would you like us to bring?  
What can my loved one do beforehand to prepare for treatment?  
How long will the treatment take?  
Can my loved one go to and from treatment alone? Should someone else go with him?  
Can I or another family member be with my loved one during the treatment?  
What can I do to help her 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?  
How does filing insurance claims work? Who can help us if we have questions or problems?

### 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, people who have their pain managed are able to focus on healing and on enjoying life. If someone is preoccupied by pain, you may notice personality changes. These might include being distant, not being able to sleep, or not being able to focus on daily activities.

The medical team should ask regularly about pain levels, but it's up to you and your loved one to be open about any pain. The patient 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 loved one's treatment. The key is to talk regularly with the health care team about pain and other symptoms.

Sometimes people with cancer don't want to talk to their health care team about their pain. They worry that others will think that they are complaining or that pain means the cancer is getting worse. Or they think that pain is just something they have to accept. Sometimes people get used to the pain and forget what it's like to live without it.

This is when it is important for you to encourage your loved one to speak up. Or you can speak up on his behalf. Be honest with the doctor about pain and how it is affecting the daily routine. You and your loved one may need to have talks at different times to continue to feel comfortable about the pain medicines given. These 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 your loved one needs them. Addiction is rarely an issue in people with cancer. Instead, drugs help patients 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 a second opinion. And many health insurance companies will pay for them.

If your loved one gets a second opinion, the doctor may agree with the first doctor's treatment plan. Or the second doctor may suggest another approach. Either way, your loved one has more information and perhaps a greater sense of control. You both can feel more confident about the decisions you make, knowing that you've looked at your options.

Talking with Family and Friends

Helping Children and Teens Cope

Ways to Stay Involved in Your Children's Lives

How Children May React, and What to Do\*

Tips for Talking With Children of Different Ages

Communicating with Your Partner with Cancer

Communicating with Other Family Members and Friends

And remember, Passionate Care LLC is here for you, so contact us if you need our assistance. 419.445.0002