

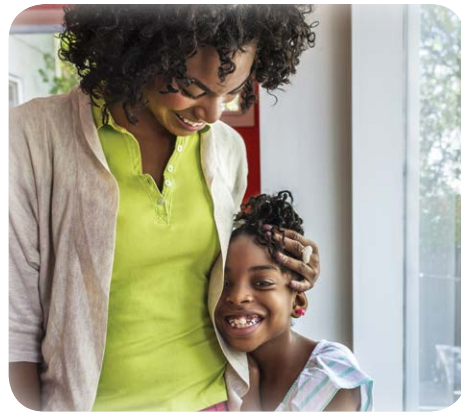
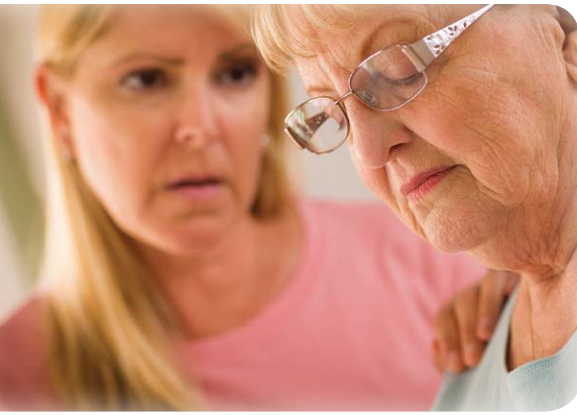
# A Communication Guide for Caregivers



**comfort**  
Communication Project

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### About this guide.

**Communication** with one another is important when someone in your family is told they have cancer. Talking about cancer affects the cancer journey for both you and the patient. If you or the patient feels nervous or sad, these feelings can affect how you communicate with each other and with doctors and nurses.

“What is family”?

Family can be your spouse, partner, children or “family-like” friends. Family can also be the family you were born into, like your parents/guardians and brothers and sisters.

We developed this guide for the **family**. This guide is based on **four main ideas**:

- The patient needs support from the family.
- The family caregiver should also be supported.
- Cancer affects the patient’s body, heart and mind.
- Communication is a process created among patient, family and health care providers.

We are glad to offer this resource to help families talk about cancer. We hope that this guide will give you some tools to use in the time ahead.

# Communication with the Patient



- How do I take care of someone with cancer?
- What should I share with the patient/family member?
- What if we don't agree?

## How do I take care of someone with cancer?

- Susan has been married to Henry for 20 years. She knows that when he goes alone to clean the garage, he is having very strong thoughts and feelings about something. He is not ready to share those thoughts and feelings.

You share how you feel by the way you say things and the way you do things — like the tone of your voice or the way you walk through a room.

Miguel, for example, was rushing to work when he discovered that his wife had wet the bed during the night. Out of frustration, he said:



- “ I told you to let me help you go during the night, but you had to do it your way. You have no idea how late this is going to make me.” And then almost immediately, he was sad about hurting his wife who had lost so much in so short a time. When he looked at the expression on her face, his eyes filled with tears.

The patient will react to how you communicate. Be aware that you affect one another by what you say and how you say it. Talking about ideas, words, feelings and thoughts is what communication is all about. Begin by talking about how it feels to be a caregiver.

# What should I share with the patient/family?

The way you talk to others about cancer depends on so many things. Your own ease and comfort is a big factor, as well as your relationship with the patient. What your family expects from you impacts what you talk about with the patient.



As a caregiver, you may feel like you can't tell the patient how you are feeling, what you worry about, how you miss doing other things and what you are afraid of. Each caregiver is faced with making decisions about what to tell or not tell the patient or others. Sometimes telling a person other than the patient is helpful. It is important to share your feelings and concerns and to be heard — whether you share with someone at home or outside of the home.

> Marty's wife, Tina, was 38 years old when she was diagnosed with Stage 2 breast cancer. She was enjoying her fifth year as principal of an elementary school. Marty says, "She didn't want others to know about the cancer, especially our kids and people at her work. Her mom died of breast cancer when Tina was 10. It was hard for me to come up with reasons for why she wasn't feeling well."

## Talk about ...



> Tanisha, a 54-year-old woman who is caring for her mother with ovarian cancer, explains about her family: “It’s like if you don’t talk about it (the cancer), it will go away. My family doesn’t know how to deal with these things. I don’t know where to go with it and I am less and less productive. Not sharing just makes things worse.”

### YOUR BODY

Caregiving takes a toll on your body. A caregiver can struggle to find sleep and eat well. Many caregivers ignore their own aches and pains that need attention.

“ I haven’t been to my own doctor in months. I just don’t have the time. One day, my daughter noticed that I was having a hard time opening a jar in the kitchen. She made me go to the doctor. I had a sprained wrist. I knew my wrist hurt from lifting my mom, but I couldn’t stop long enough to go see my own doctor.”

### YOUR MIND

Taking care of someone with cancer is difficult and can be overwhelming. You may feel like it’s hard to keep up with all the medical information and decisions. It can be harder to concentrate, harder to make decisions and harder to care for the patient.

> Margie is caring for her husband, Tom, who has renal cancer. She has tried hard to keep up with all of his medications, appointments and instructions for care. She tells her friend Beth, “I feel like I’m losing my mind. I forgot to schedule Tom’s lab work and I think I missed giving him his meds. My brain is on overload, and I almost forgot to go pick up my son after school yesterday.”



# Talk about ...

## YOUR TIME

As things change for the patient, they change for you, the caregiver. People you once had time to see or activities you once enjoyed are no longer possible with your new caregiving responsibilities.

## YOUR HEART

You will have times of peace, doubt, hope, fear and more. The patient may be able to help you with these matters of the heart. But you may feel you do not want to worry the patient.



Seven months into caregiving, Juana realized she had taken less and less time to journal, something she did to reflect on her fears, frustrations and joys. She was almost ashamed to take a few minutes away from her mother to do this for herself, and so she quit journaling.



# Sharing information

When you first learn your family member has cancer, you may want to know more about the disease, how to treat it and about the hospital. You may turn to the Internet and friends to find information. Once you have new information, you have to decide whether or not to share it with the patient.

## THINGS TO CONSIDER ABOUT SHARING

- Why do I want to share this information?
- Why am I afraid to share this information?
- How does this information affect the patient?
- How does this information affect me?
- Would the patient want to know this information?
- How does this information affect me as a caregiver?

## HERE ARE WAYS YOU CAN SHARE:

- "I want to tell you about something new I learned about your cancer."
- "In my heart, I know you will want to know this. Today, I learned more about the treatment and how hard it is going to be for you and for me."
- "The doctor came in after your biopsy and let me know the cancer is in other places."
- "I had a really good conversation with the nurse last night. He told me about a kind of care called hospice."
- "We've always been very close, and I want you to know what I know about your cancer. The Internet says that the chemotherapy you are getting doesn't cure the cancer."

If you decide not to tell the patient about information you learn about his/her cancer, you should still think about talking with a doctor or nurse about your decision not to share with the patient. It is important that you tell others your concerns. They may be able to give you support.



## WHAT TO TELL OTHERS

As a caregiver, you will have news to share about the patient's cancer. The relationship you have with the patient will help you decide what information you keep private, and what information you share with others. Sharing news depends on who is asking for information and the advantages or disadvantages in sharing. Disagreeing with the patient about sharing news can create additional stress for you.

➤ A 64-year-old woman taking care of her mother with lung cancer explains: "When my mom and I found out that her cancer had spread to her brain, she didn't want to tell my brother. He had just lost his job, his youngest son had been really sick and he lives several states away. I told her, 'What am I supposed to say when he asks how you're doing?'"

### YOU MAY NOT WANT TO TELL OTHERS BECAUSE:

- They may misuse the information.
- You feel that you do not need help.
- You don't want them involved.
- You don't want to interrupt their life.
- You don't want to cause them stress.

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## What if we don't agree?

Chances are, there will be differences in what you and the patient think and want. Disagreeing is OK. What is important is learning how to communicate when you disagree.

Disagreeing is common. The patient and you have shared experiences that will affect what you talk about, and how you handle differences. Agreeing to disagree can make your relationship stronger. But it can also be very stressful, and you might need to find someone to share your concern and frustration.



During the cancer experience you and the patient, if he or she is able, will be faced with many decisions. Treating cancer should include choices that make the best life possible for the patient

### FINDING HOPE IN THE CHOICES YOU AND THE PATIENT MAKE

- How to live
- Who to spend time with
- What activities/work to pursue
- Things to experience

# Communication with Other Family Members



## 2

- Who is family?
- How do I talk about cancer with my family?
- Why is talking about cancer difficult?
- How can my family help me?

## Who is family?

“ Even though we haven’t been a married for a couple of years, I was married to her for a decade and raised her kids. I know her well. All her kids do is call every couple of months. When she found out she had cancer, she called me first. I’ve always taken care of her and I always will,” explains Demetrius about caring for his ex-wife.

Each person will think of different people as family members. For example, a close friend of yours may be family to you, but not to the patient. As you take care of the patient, the people you consider family are family. They will support, challenge and need you. They will make the job of taking care of your loved one easier or harder.



“ We’ve just always been friends. I met her in grade school when she was 14. We’ve stayed in touch, gone to each other’s weddings, saw each other once every couple of years. All of the sudden we were living in the same city, across town from one another. It was not a surprise to me when she asked me to be her power of attorney. Her husband hasn’t spoken to me since she signed the paperwork.” – Alice, age 67

### MAKE TWO LISTS

Make two lists of family members involved in your life. The first list should include family members who might be supportive to you and/or the patient. The second list should include family members who might not be supportive. List the reasons why you feel this way.

# How do I talk about cancer with my family?

Suddenly, everyone is looking to you for news, updates and explanations about the patient's cancer. It may feel like a carousel going 'round and 'round with people constantly calling you. Sharing news about cancer is part of caregiving. But it may be difficult to manage.

Do you see yourself in one or more of the following caregiver descriptions?

## THE WAY YOU TALK TO YOUR FAMILY DEPENDS ON:

- Your relationship with each family member
- What you think each family member needs from you
- What you think each family member wants to hear from you

## CARRIER CAREGIVER

You might find yourself in a family that does not talk about cancer. Your family may typically avoid conflict. The family is around you and the patient, but you find yourself caring for your loved one by yourself. This is fulfilling, but it also leaves you with little time and energy for anything else, including yourself. The patient makes the decisions, and you make sure those decisions are put into action. Family members could share some of your stress, but it is hard for you to accept or ask for help.

### WORDS OF ADVICE:

- Challenge yourself to ask for help today.
- Tell the patient what you have to do today.
- Take 20 minutes for yourself today, even just to sit by yourself or listen to your favorite music.

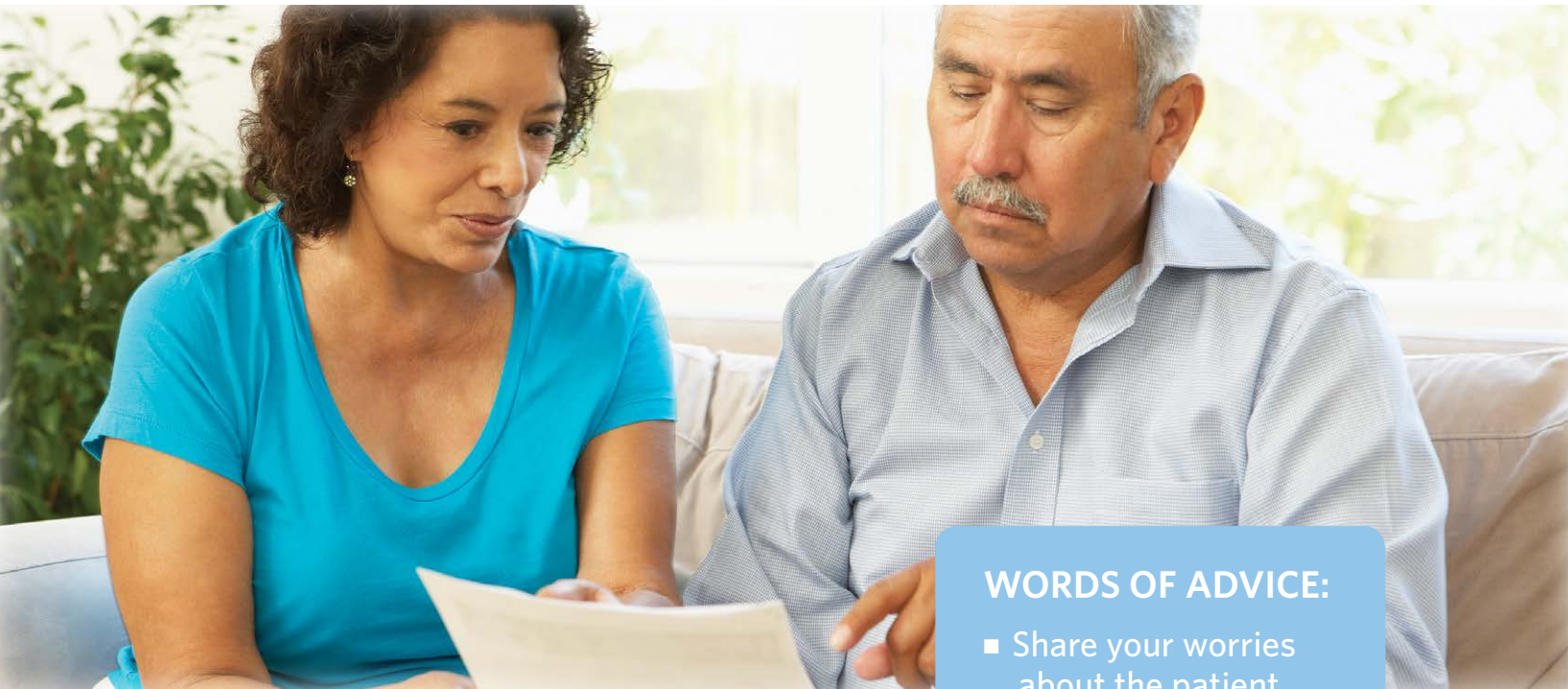



Rahmil's 24-year-old son had just begun treatment for testicular cancer. His other son, age 30, became very depressed following his brother's diagnosis. Rahmil says, "It's always just been me. Their mother died when they were teenagers. I'm taking one son to his radiation appointments and the other to the mental health center. I'm glad I am able to do it."

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## MANAGER CAREGIVER

You may stay on top of every aspect of the patient's cancer. Leading the family in decisions about cancer and treatment is very important to you. In fact, you are probably the main speaker in medical appointments and in talking to your family. The patient defers to your ideas and care decisions. Your family enjoys regular contact and conversation and focuses on the positive. You may see yourself as a researcher about cancer and related medical information.



 Lupe, age 55, caring for her father diagnosed with Stage 4 lung cancer describes: "My sister helps with my dad. I have to teach her about what is important and how to do things because I am the one who talks to the doctor and calls the nurse."

### WORDS OF ADVICE:

- Share your worries about the patient with another family member.
- Ask the patient how he/she thinks things are going.
- Put down your "to do list" for one afternoon and do something relaxing.





We were waiting for my mother to finish getting a PET scan. It had been a long day. My father turned to me and said, 'We have to take better care of ourselves if we are going to be able to do this.' He was right. It was already late and I hadn't had a thing to eat or drink."

## PARTNER CAREGIVER

You may receive help from many family members, as well as the patient. Family members do what they can to share caregiving. Your family talks openly about cancer and shares different ideas. When family members disagree, they talk about the disagreements and come to a solution. The patient is concerned about you, how well you are doing and how cancer is impacting your life. Family members help you find time for yourself.

### WORDS OF ADVICE:

- Invite a family member to fill in for you for a day.
- Share with the patient how you are grateful for him/her.
- Eat three healthy meals today.

## LONE CAREGIVER

You may be the only person caring for and making decisions for your patient. The patient relies on you. It is likely that the patient has many needs that concern you. You might feel frustrated with your family for not helping more. It is hard to find help and you have little energy for yourself.

### WORDS OF ADVICE:

- Spend 10 minutes writing about one thing that would help you during the next week, and how to do it.
- Say “yes” to one offer of help and see how it works out.
- Call a friend and ask how he/she is.



Tom had been diagnosed with liver cancer. Crystal recalls, “It had been a rough couple of hours. Tom had a lot of pain and finally drifted off to sleep around 10 p.m. It was the only “good” time to get groceries so I went to the store. I ran into Tom’s brother who was also shopping. He lives two blocks from us, but never comes to visit. I watched him easily stroll through the produce section. Our eyes met and he quickly nodded his head and walked away. He could have at least asked me how his brother was doing.”



You may feel like you are similar to one or more of these caregiver descriptions. Every caregiver needs and deserves help. Try to find a new way to take care of yourself, as you care for the patient.

## Why is talking about cancer difficult?

Communication about cancer can be spoken or not spoken. Our words, or our silences, express our feelings and thoughts. We can be hurt or we can hurt someone else with the words we use or by saying nothing at all about cancer.



## How do you communicate with those in the family who won't talk about cancer?

- Just 'be' with them and remove the pressure to talk.
- Ask how they are.
- Share one thing in your own life that is hard.
- Give yourself and them a time limit. ("I have five minutes and thought I would call.")
- Let other family or friends pass on information to them.

## Think about how you talk about the patient's cancer:

- What words do you use or not use with certain family members?
- Do you avoid or make eye contact when talking about certain cancer issues?

## OPTIONS THAT WILL HELP YOU RELAY NEWS

- Family meeting
- Facebook page
- Group texting
- Group phone call
- Communication chain (choose one family member who will contact another family member)
- Group email (choose one family member to email a patient update)

## COMMUNICATING ABOUT CANCER CAN BE HURTFUL BECAUSE OF:

- The **way** words are said (tone of voice)
- The person's **body language** (face, eyes, timing) when words are said
- **When** the person chooses to share
- A **history** with the person who says it
- The immediate **circumstances** in your life



Identify someone in your family whom you find most challenging:

In the box below, write what makes them challenging to you as a caregiver:

### HOW TO START A CONVERSATION ABOUT HURT FEELINGS:

- "I know that all of us are dealing with new things right now ... "
- "The best way I can take care of [patient] and me is ... "
- "It would really help if you would ... "

# How can my family help me?

“ Let me know what you need. Anything at all.”

“We are here for you. We can help. Just let us know what we can do.”

“Call me if you need anything.”

“Si necesitas algo, dejame saber, mijo.”



These may be familiar words you have heard from family. Help may be available, but you have to ask for it when needed. Every caregiver needs help. Learning to ask for help and telling others what you need can lessen your stress.

Perhaps you believe that the people in your family cannot help with the problems you face. Or you may want to protect them from what they may see or experience. If someone has offered help, it is OK to say yes! Let them know what you need. No one knows better than you what those needs are.

## HOW TO ASK FOR HELP:

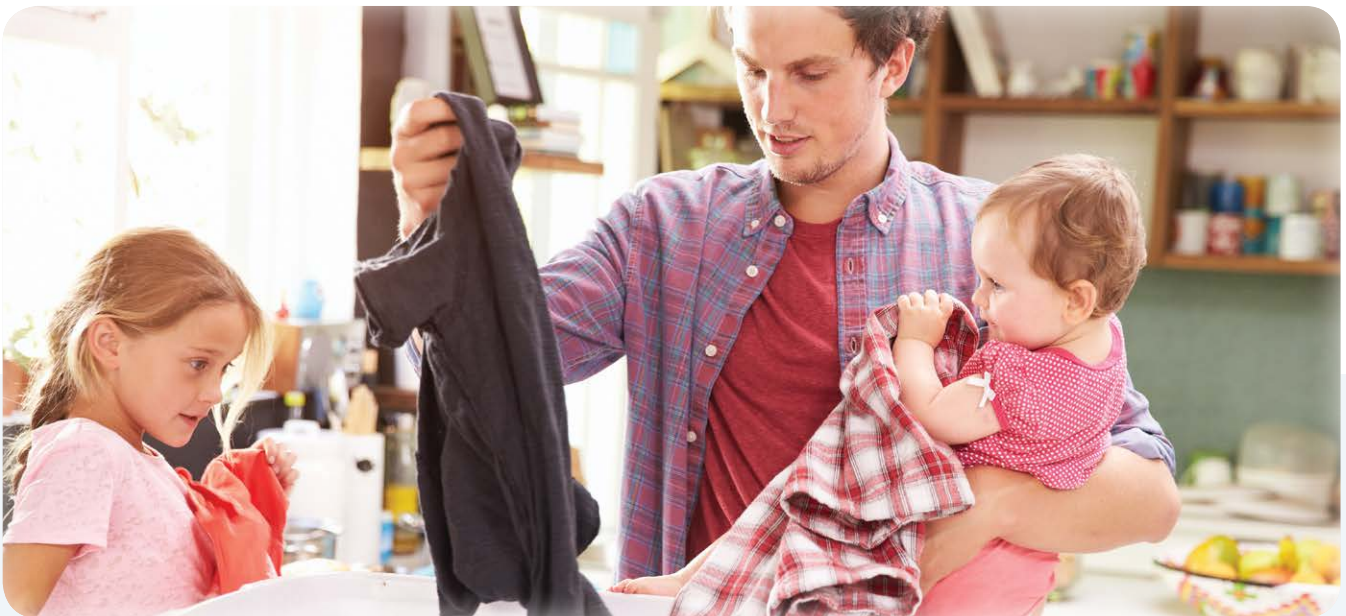
- Explain the problem you have.
- Tell the other person the help that you need.
- Describe how they can help.
- Explain how this will help you.

## HOW TO REDIRECT AN OFFER THAT IS NOT HELPFUL:

- Thank the other person.
- Recognize their offer of help.
- Tell them if their offer creates other problems.
- Explain that you cannot accept their offer.
- Suggest another way they can help.

## EXAMPLES OF ASKING FOR HELP:

- “He takes a lot of medicine. His medicine is ready to be picked up at the pharmacy. Could you stop by the pharmacy on your way over and bring it with you? That would really help me, because it’s hard for me to get out of the house right now.”
- “With so many people coming over, I haven’t been able to find five minutes alone for myself. Would you mind if I didn’t stay when you came to visit her this afternoon? I would like to go over to the park for half an hour and walk. That would really make my day better.”
- “The house is a mess and I’m so embarrassed when people stop by to see him. I need help cleaning and organizing all of this medical stuff in the dining room. You are so good at getting things in order.”



### Example of Redirecting an Offer

- “Thank you for making the effort to travel here to visit Lonnie. I know you wanted to cook a meal for everyone. But it just won’t be possible because of the smells it will create and the extra bustle in the house. What I would really appreciate — and I know Lonnie would, too — is if you could bring in his favorite ice cream and enjoy it with him in his room.”

Learning to ask for help is one very important way you can take care of yourself while taking care of the patient.

# Communication with Family Members Who Are Far Away

## 3

- What is it like to be a family member far away?
- What does the cancer journey look like?

## COMMUNICATION WITH FAMILY MEMBERS WHO ARE FAR AWAY

### What is it like to be a family member far away?

A family member who has to travel more than an hour may feel less included in caregiving or even guilty because he or she is unable to be with the patient and family. Remember that family members who live far away may still want to be involved in caring for their loved one.



### INVOLVING FAMILY WHO ARE FAR AWAY

If you are the caregiver who lives close by, you have an important role in keeping family who are far away up-to-date. Help them understand how much the patient is able to do on his or her own and how he/she has changed physically. This will help them figure out how they can help from a distance. Talking to other family members about the cancer and the patient gives you the opportunity to ask for their help, if you need to.

### WAYS TO HELP GIVE CARE IF YOU ARE FAR AWAY

- Offer to make phone calls or handle financial tasks.
- Call the caregiver and/or patient and listen to their worries, fears.
- Send money or pay for services that would aid in caregiving.
- Research information on diet, exercise, treatment.
- Volunteer to care for the patient for a few days to relieve the on-site caregiver.



## Things to tell family members who are far away:

- Tell them your fears, concerns, needs.
- Help them learn more about cancer by suggesting a website or book.
- Describe the treatment, how it will work and what it will be like.
- Tell them how the patient will change or has changed, both physically and mentally.
- Talk about any problems you and the patient are having.



## You can also send the following:

- An email/card that has words or thoughts from the patient
- Website links that describe the cancer and diagnosis
- A calendar with treatment dates and appointments
- A specific request for something you and the patient need
- Updates and pictures about the cancer journey
- Sharing good news about successful treatments or remission

## WAYS TO COPE AND COMMUNICATE IF YOU ARE FAR AWAY

- Ask the patient to talk about the high and low point of the day.
- Plan a visit when you can go meet health care providers.
- Schedule a video chat.
- Have phone contact with one of the patient's health care providers.
- Arrange to be included in appointments by phone.
- Request a patient advocate/navigator where the patient receives care.
- Make sure your travel includes time to rest when you return.
- Use the Internet or local library to find caregiver resources.

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## What does the cancer journey look like?

Use the following worksheet to help you give information to far away family members. It is a way to see the course of treatment over time. It may help you understand how the patient has felt and what should come next, as you think about caregiving.

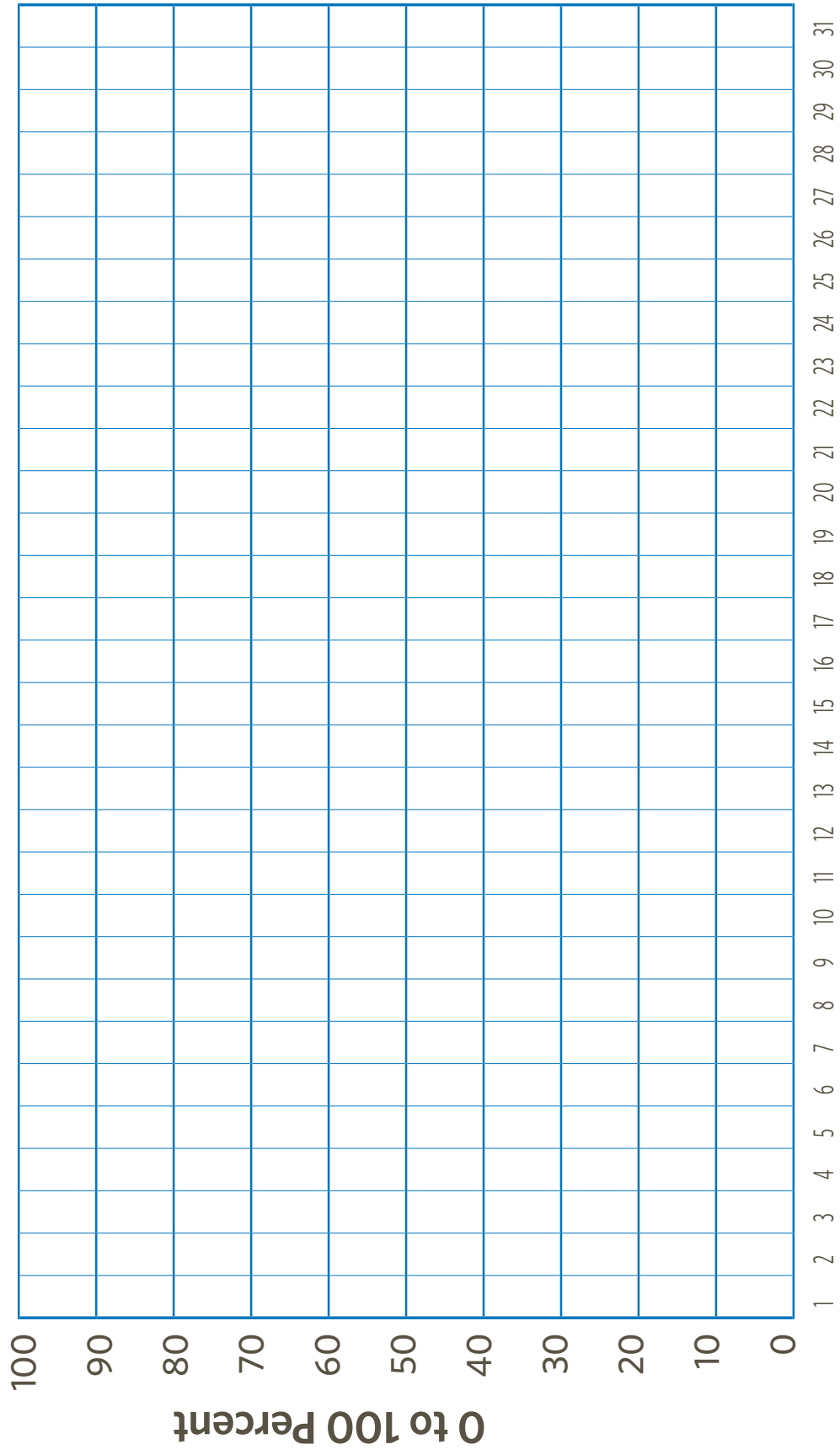


### How to Chart the Cancer Journey

1. The graph has two sides. The side going up and down has numbers counting by tens. These numbers are percentages. These numbers represent how good the patient is feeling in terms of the heart, mind and body.
2. The bottom side of the graph, from left to right, has the number of days in one month. Fill in the day of the month and each day, ask yourself: "How good is the patient's heart, mind and body today?" Thinking about it in terms of percentages, 0 to 100 percent. Place a dot on the graph that represents how good the patient's heart, mind and body feels.
3. Repeat this each day until you have recorded a full month.
4. Finally, connect the points on the graph. This will show a pattern of how good the patient's heart, mind and body have been over the last month.

The completed graph can be shared with family who are far away. Think about the last month. What may have caused the patterns on your chart?

# Chart the Patient's Heart, Mind and Body



Insert month: \_\_\_\_\_



# Communication with Health Care Providers



- What do health care providers need from me?
- What can I ask a health care provider?
- What if I can't do what is asked?

## What do health care providers need from me?

Health care providers will work with you and your loved one to develop a care plan. This is a list of all the treatments the patient will receive. The care plan is based on the patient's beliefs and values. This is where you come in.



### YOU CAN TELL THEM:

- Where the patient was born and raised
- What language the patient and you prefer to speak
- If the patient has a preference for a male or female provider
- Any foods the patient would especially enjoy, or especially want to avoid
- Any customs or family rituals that should be included in the patient's care



Health care providers may use words you have never heard before. The list of words below will help you understand how they will talk about cancer. If you hear a word that you do not understand, ask a health care provider to explain it.

What you might hear ...	What it means ...
Adjuvant therapy	Extra treatment that works with your main treatment, such as chemotherapy and surgery
Benign	Does not hurt you; not cancer
Biopsy	Getting a sample from your body
Chronic	Always; lasts a long time
Clinical trial	Testing a new drug
Consent	Give permission; agree; say OK
Dyspnea	Trouble breathing
Localized cancer	The cancer is only in one part of the body
Malignant	There is cancer in the body; it gets worse over time
Metastasis	The cancer grows and moves to other parts of the body
Palliative care	Health care that attends to all of you, not just what is making you sick; helps with pain
Prognosis	A guess for how things will be in the future; what the illness will be like in the future
Staging	The size and place of cancer in the body

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# What can I ask a health care provider?

Things have changed in health care. A long time ago, only doctors and nurses had information about cancer. Today you can get information about cancer from the Internet and from other people you know. Take a look at the list of things you can ask, and some suggestions about how to do it.



## ASK HEALTH CARE PROVIDERS FOR:

- Copies of test results, medical chart
- Explanations about cancer or treatment
- Time to discuss your concerns
- Answers to questions

### You can say:

"I would like a copy of ..."

"Can you go back a little and explain how the chemotherapy ..."

"The part that is not clear to me is ..."

"I have been watching her and what I see ..."

"I have some questions ..."





### ASK HEALTH CARE PROVIDERS ABOUT:

- Addressing conflicts
- Getting another opinion
- Doing things differently
- Talking with other family

### You can say:

"I understand what you are saying. However, I am really concerned about ..."

"Here is what I am worried about ..."

"We want to understand the options ..."

"We want to ask another oncologist ..."

"What we have been trying is too hard for us ..."

"Would you be willing to meet with my mother again and explain ..."

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## What if I can't do what is asked?

Health care providers do not know what you can and cannot do. You must tell them if you are uncomfortable or if what they are asking you to do is impossible.



Being a caregiver doesn't mean you have to do the impossible. Here are some ways for you to practice talking to a health care provider. It is hard to tell someone that you cannot do something, but health care providers need to know.

### WHAT MAY SEEM IMPOSSIBLE

- Oncologist: "The good news is that you can do this after surgery care at home and recover in your favorite place."
- Daughter of patient: "So, how will we manage the catheter? The nurse said it would be needed for another week."
- Oncologist: "We will train you so that you know how to do this by the time you leave here."



### How to Say It's Not Possible:

- "... I won't be able to do that part of her care."
- "... I need to talk about a different schedule for her radiation."
- "... Can you help us find some evening care? I am not at her home all day and night."
- "... What other ways are there?"
- "... I can't wake up all through the night to give her medicine."
- "... This is something I can't do."



## RECOMMENDED SUPPORTIVE CAREGIVER WEBSITES

Website	Website Description
Cancer Care: <a href="http://www.cancercare.org">www.cancercare.org</a>	Provides online support, including the availability of telephone support with an oncology social worker.
Cancer Support Community: <a href="http://www.cancersupportcommunity.org">www.cancersupportcommunity.org</a>	An international organization to ensure that all people impacted by cancer are empowered. Provides knowledge and cancer education workshops.
Caring from a Distance: <a href="http://www.cfad.org">www.cfad.org</a>	Website specifically for distance caregivers. An independent nonprofit organization especially helpful for crisis and emergency assistance.
National Family Caregivers Association: <a href="http://www.nfcacares.org">www.nfcacares.org</a>	Provides information, education, support, public awareness and advocacy for caregivers. Links to long distance caregiver stories.





