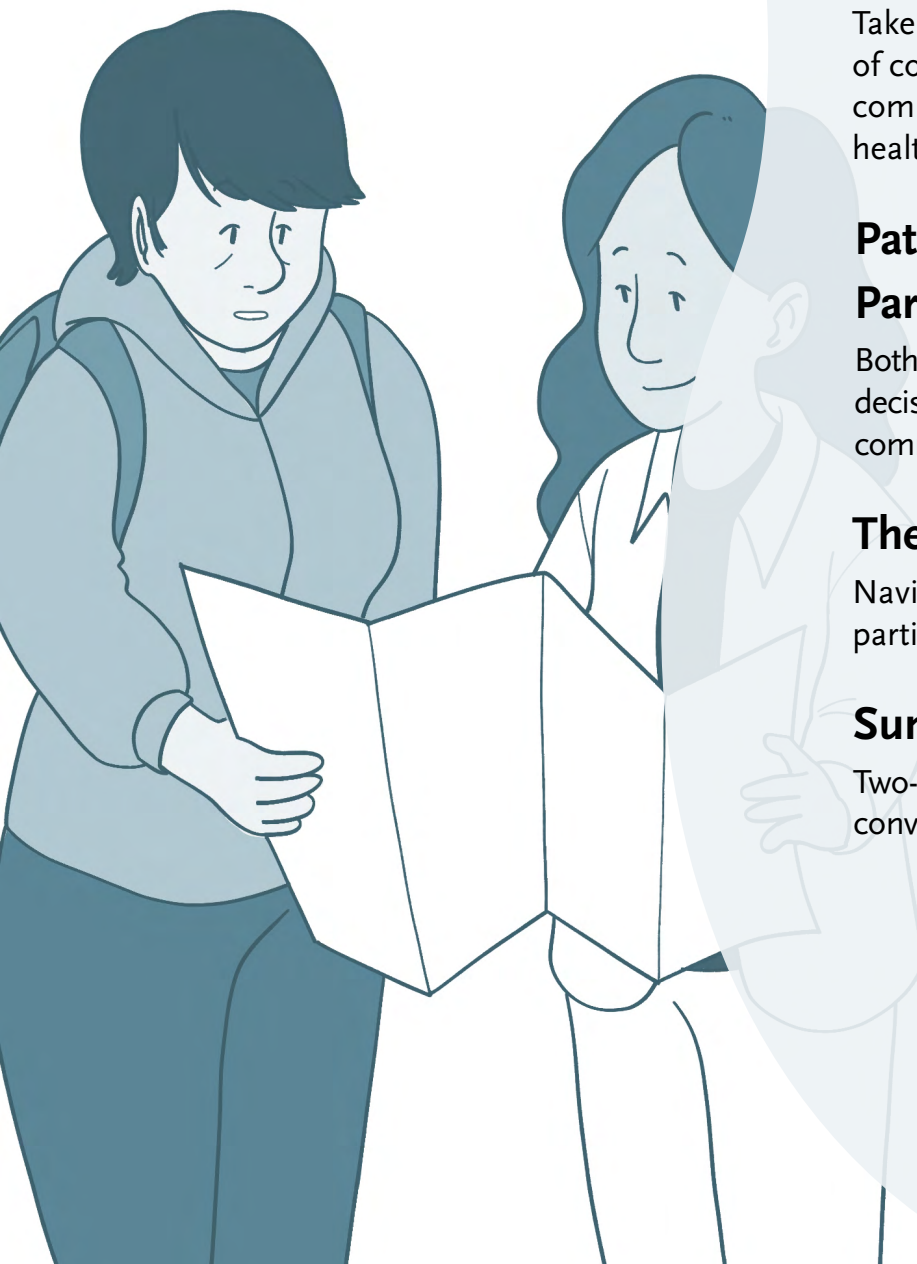


Communication with Healthcare Providers



The Healthcare Team

Learn about the different roles of the members of the healthcare team, **pg.54**

Communication with Healthcare Providers

Take a moment to reflect on the importance of communication and learn about some common communication barriers in healthcare settings, **pg.57**

Patients and Caregivers as Care Partners

Both your roles in the healthcare team, your decision-making styles, and pattern of communicating with healthcare providers, **pg.64**

The Caregiver Role

Navigating the healthcare system and participating in treatment decisions, **pg.71**

Summary

Two-page summary with starters for difficult conversations, **pg.75**

The Healthcare Team

Patients and their caregivers speak to many healthcare providers during cancer care. This may include healthcare providers from many different specialties. They may be responsible for helping patients manage their treatments, symptoms, and treatment side effects, emotional concerns, and offering information and resources related to cancer.

Members of Your Healthcare Team

Oncologists

Oncologists are medical doctors (physicians) who specialize in the treatment of cancer. They have received training in the treatment of cancer using different types of treatment. An oncologist is usually the main healthcare provider for someone with cancer.

There are different types of oncologists, including a radiation oncologist who specializes in using radiation to treat cancer, a surgical oncologist who specializes in performing surgery to treat cancer, and a medical oncologist who specializes in diagnosing and treating cancer with chemotherapy and other drugs. Your oncologists may also consult with other medical specialists to treat non-cancer related problems.

If you are getting treatment at a teaching hospital, your oncology team may also include medical learners that may be called medical students, residents, or fellows.

Palliative Care Physicians

The palliative care service is focused on symptom management and advance care planning. Palliative care is a medical specialty, but palliation can be provided by family doctors or other

health care providers. The palliative care team may follow patients while they're also receiving cancer-focused treatment.

Nurses

This group of professionals includes Registered Nurses (RN), Registered Practical Nurses (RPN), Advance Practice Nurses (APN), Nurse Providers (NP) or Clinical Nurse Specialists (CNS). They each have different qualifications, training, and responsibilities.

Nurses will be at your side throughout your experience with cancer. They can provide you with daily care in the hospital, in the community or at home, answer questions about your care and provide emotional support. Depending on their level of training they may also be able to diagnose and prescribe medications. Some nurses receive special training in particular areas. For example, you may meet Clinical Nurse Specialists who focus their practice on working with patients in palliative care.

Social Workers

Social workers can help you and your family with emotional and practical needs. This includes emotional support, strengthening coping strategies, communicating with your family, the person you're caring for or health team, planning finances, and more. They can also give you information about services and supports in your community.

Psychiatrists

Psychiatrists are medical doctors who specialize in the treatment and prevention of mental, emotional, and behavioural problems. They can provide counselling, consultations, and drug therapy for both patients and their family members.

Psychologists

Psychologists are mental health professionals with a graduate degree in clinical psychology. They specialize in assessing and providing treatment for mental health conditions, emotional distress, and behavioural disorders. They can also help you with treatment planning and give you strategies to overcome cancer-related challenges.

Music and Art Therapists

Music and Art Therapists can help you express your feelings and cope with your diagnosis in creative ways.

Spiritual Care Providers

Spiritual care providers help people explore their sources of meaning in life and hope. They can help you cope with difficult times, to find meaning and value in life, and connect with others.

Dietitians

A dietitian is a health professional trained in nutrition and diet. They can teach you about choosing the right foods, including giving advice

on recommended dietary changes due to cancer or cancer treatment.

Pharmacists

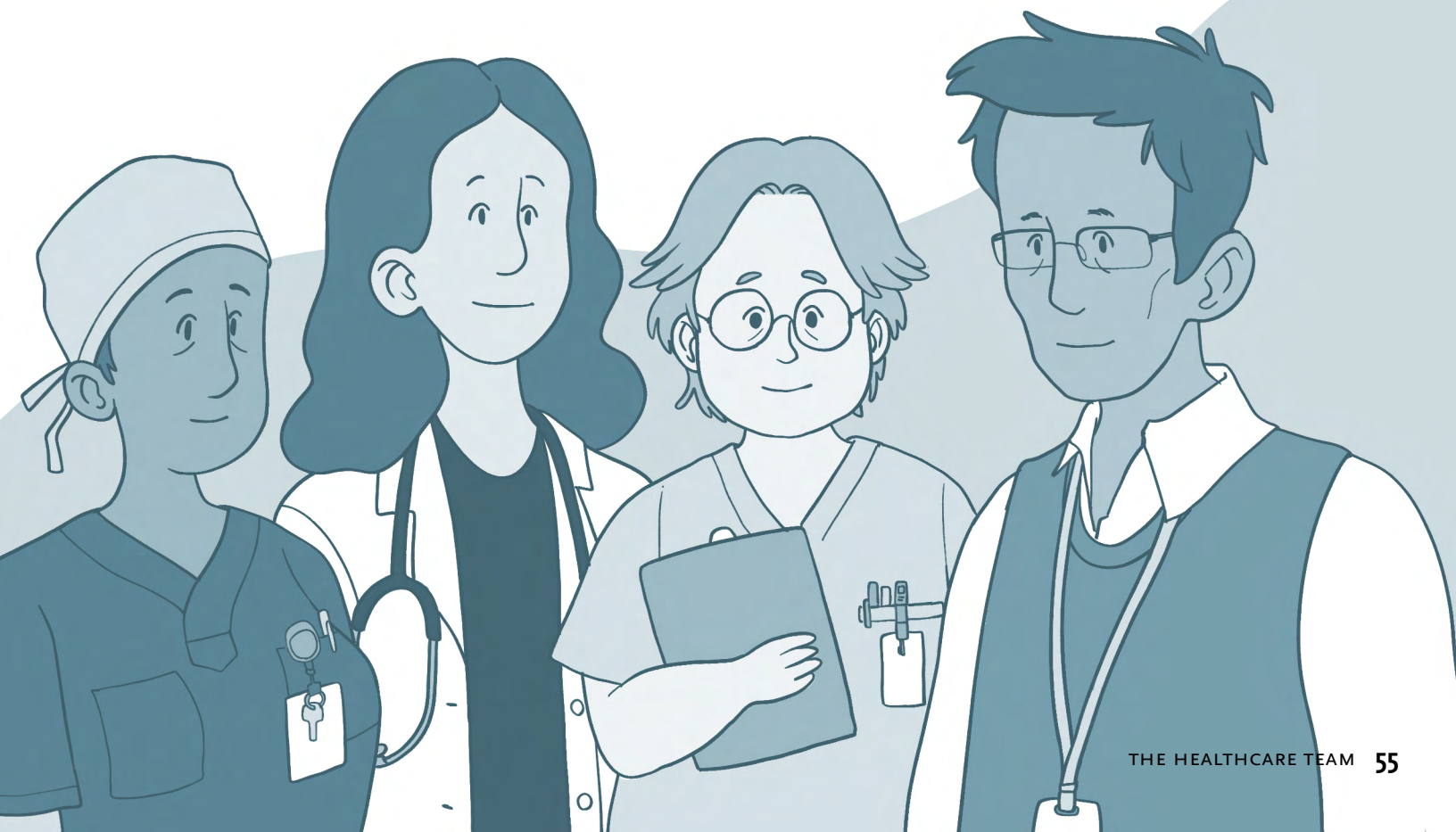
Pharmacists prepare medication, such as cancer drugs or pain medication. They can explain how to take the drugs, how they work, and their potential side effects. Sometimes they can also administer certain vaccines.

Occupational Therapists

Occupational therapists can help you maintain your daily activities, such as adjusting your work activities based on your abilities. They can also help you make changes to your home based on your changing needs.

Physiotherapists

Physiotherapists or physical therapists are trained to treat people with conditions or injuries that affect their ability to do physical activities. They can help you with strength, balance and coordination. They can teach you exercises to help you maintain or restore fitness.



Your Relationship with the Healthcare Team

Why do some people feel supported and understood by their healthcare team while others may feel they cannot count on their team or speak freely?

Where is the person you are caring for receiving care for their cancer and who are the most important members of their cancer care team?

Are you involved in communication with their healthcare team? If so, how or how not? How might you like to be involved?

Communication with Healthcare Providers

In any relationship, effective communication is important and the ability to feel comfortable talking openly with the team is important when discussing the cancer diagnosis and cancer treatment. The members of the healthcare team have a major role in managing the patients' health.

Take a moment to reflect on your communication with the healthcare team.

Are you and the person you are caring for able to have conversations with the team that help you understand their disease, symptoms and make treatment decisions? If not, can you think of what the barriers or obstacles may be?

You may find some individuals easier to approach than others, and if so, can you say why?

Think of a time when difficult or positive news was communicated to you both? How did you feel at the end of the interaction? Can you identify what helped or did not help that interaction?

Josephine's Story

Josephine is a 72-year-old woman who has recently been diagnosed with stage four breast cancer with bone metastases. She recently discovered that her chemotherapy is no longer working.

Josephine, I'm so sorry to hear that your chemo isn't working anymore.

But I'd like to chat about a new treatment plan!

As her medical oncologist talks about the treatment plan, Josephine is lost in thought.

I didn't catch that word. I'll ask her after she finishes. I don't want to interrupt.

She seems hopeful this will work. And I trust her.

I need her to go into more detail...

I don't understand how this is different from my chemo.

Before I take off, do you have any questions for me?

Yes! Maybe I'll ask a few.

No, I'm good. Thank you doctor.

Why couldn't I ask her?

Well, let me know your decision soon!

Please take a moment to reflect on any communication problems with the healthcare team.

What kind of communication problems has the person you are caring for experienced?

What kind of communication problems have you experienced?

What did either of you do about them?

Is there anything you or the person you are caring for might do differently if these problems are experienced again?

Did experiencing these problems affect how you were feeling about your care?

Communication Challenges

Most people have experienced long wait times to see their doctor, only to find that their appointment is quite short. Doctors on the care team may not always be able to spend as much time with you as either of you would like. It may be helpful if you clearly communicate your most important concerns first. Nurses and other health care providers can also be important sources of information.

Most people do not have a background in medicine. Learning about cancer can be like learning a new language. Healthcare providers use words that many people may not be familiar with.

Many patients don't feel confident in their ability to understand information. Some people question their own personal knowledge and the value that they can bring to the conversations with their healthcare team.

You, the person you are caring for and the healthcare providers may have certain styles or approaches to communication that may be more or less effective.

Some people want as much information as possible, but others prefer to only receive information that is necessary to make decisions about their care in that moment. Healthcare providers can sometimes make assumptions about what and how much information people want.

Some people find it intimidating to speak to healthcare providers. They may find it hard to speak up when they have questions or do not agree with their care provider. This can be because there is a power imbalance between provider and patient. It might surprise you to learn that research has shown that even doctors can have trouble speaking up when they are the patient themselves.

Having a good relationship with their healthcare team is important to many people. But some patients might worry about upsetting their provider if they play a more active role in their care. Some people even worry that they will be seen as difficult or risk receiving lower quality care. This may be even more true for certain groups, such as older adults who grew up at a time when it was not culturally acceptable to question your physician.

The system where you are receiving care may not be as patient centred as it could be. It's not always clear who you should be speaking to or how to get the support you need.

As healthcare becomes busier and more technological, many patients and families don't feel their healthcare team addresses their emotional needs or understands who they are as a person.

Some clinicians and patients may avoid or find it difficult to talk about topics which are distressing or uncomfortable (including sexuality, disease progression, fear of death and dying and mental health issues). Because of this, some important issues may never be discussed.

Can you relate to any of these barriers?



Communication Challenges for Caregivers

Communicating with healthcare providers as a caregiver can have additional difficulties. Here are some communication challenges that other caregivers have reported:



▲ Having different information needs than the patient.

▼ Not feeling entitled to ask the healthcare team their own questions during clinic visits.



◀ Mediating the relationship between the patient and the healthcare team.

Your role in communication with the healthcare team may also change over the trajectory of the cancer care. Earlier on, it may be a more supportive role. However, as the cancer progresses and if they become unable to make decisions on their own, you may need to play a more active role in decision-making.

This can be a difficult role to play. Your opinions and attitudes may be helpful to the person you are caring for. Patients often rely on their

caregivers to aid in decision making. There may be times when you both do not agree on their healthcare decisions, and it may become challenging to support the person you are caring for while not taking over the decision-making process. It is often helpful to provide your input and discuss treatment decisions openly. Ultimately, it may sometimes be necessary to set aside your opinions to best support your friend/family member/loved one with cancer.

Tips for Communicating with Healthcare Providers

Research has found that patients and their caregivers who communicate with their healthcare team tend to have positive outcomes, including more satisfaction with care, a greater sense of control, being more informed and receiving more responsive care. It's important that you are clear with your healthcare team about the amount of information you want and what your expectations are for treatment. Here are some tips which may help improve communication with the healthcare team.

Here are some tips which may help improve communication with the healthcare team.

Be open, honest, and direct.

If you feel safe to do so, share your feelings, fears, and concerns with the healthcare team. This includes information about your physical, emotional, and social well-being, practical issues (e.g., work, money, etc.), values, goals and hopes.

These topics can be difficult to bring up with your healthcare team, but being honest with your healthcare team might help them understand and support you better.

Tell your healthcare team how much you want to know.

You can let your healthcare team know, at any time, whether you want more or less information, and how you would like to receive information. For example, some people want to know a lot of detail about their cancer and treatments because it helps them feel more in control.

Other people only like to know what is necessary because too much information can be overwhelming and upsetting. Telling your doctors how much information you want can help make your visits more satisfying to you.

Ask for clarification.

Let your team know if you want more details or don't understand something that was explained to you. There is nothing wrong with telling your team that you do not understand something. Remember, it is part of their training to learn how to explain medical information to patients.

So, by saying you don't understand, you are helping healthcare professionals become better providers.

Don't hesitate to ask your healthcare provider to spell, repeat, or explain specific terminology.

Prepare a list of questions in advance.

It can be helpful to write down questions before you meet with your healthcare providers. Ask how much time you will have during your appointment and ask your most important questions first.

Try not to worry about asking questions that you think are silly or embarrassing. Don't be afraid to ask them to simplify things for you or to ask questions multiple times. Your questions deserve answers, and your healthcare providers should do their best to answer them. It can be difficult to know what questions to ask. On the next page, we have examples of some common questions that you can write down.

If you did not have enough time during your appointment, you can ask for another meeting. Do not feel pressured to make a decision about your care at your clinic appointment if you need more time to think about it.

Take notes or ask to record your conversations with your healthcare team.

It can be challenging to remember everything during your conversations with your healthcare

providers, especially if you are nervous or scared. Taking notes may help you remember what is said and help make sure you've understood. You can review these notes after your appointment and think of any questions you may want to ask at your next appointment. If you are thinking about recording your conversation, ask ahead of time if it's okay because there can be hospital rules about recordings.

Discuss appointments beforehand.

It can be very helpful for patients to have someone come to appointments with them. They can help you take notes, ask questions, listen, and/or give support. Caregivers may want more information than the patient. Before the appointment, caregivers and patients could discuss how much the patient wants to know and could help communicate this to the healthcare team.

Keep a binder or a diary.

A binder or diary is a good way of storing all important information, such as contact information for your healthcare team, list of medication and their potential side effects, information about community and medical services, appointment calendars, diagnoses, scans, a list of questions, etc.

Ask the health care team how to contact them between appointments.

It is not always obvious how to contact the members of your healthcare team so it's a good idea to ask. You can keep a contact sheet in your binder or diary with all their information.

Some clinics have phone lines staffed by nurses to answer patient questions between appointments so be sure to ask if this service is available. Also, make sure to ask who to contact in the case of an emergency.

Coping with complex healthcare systems.

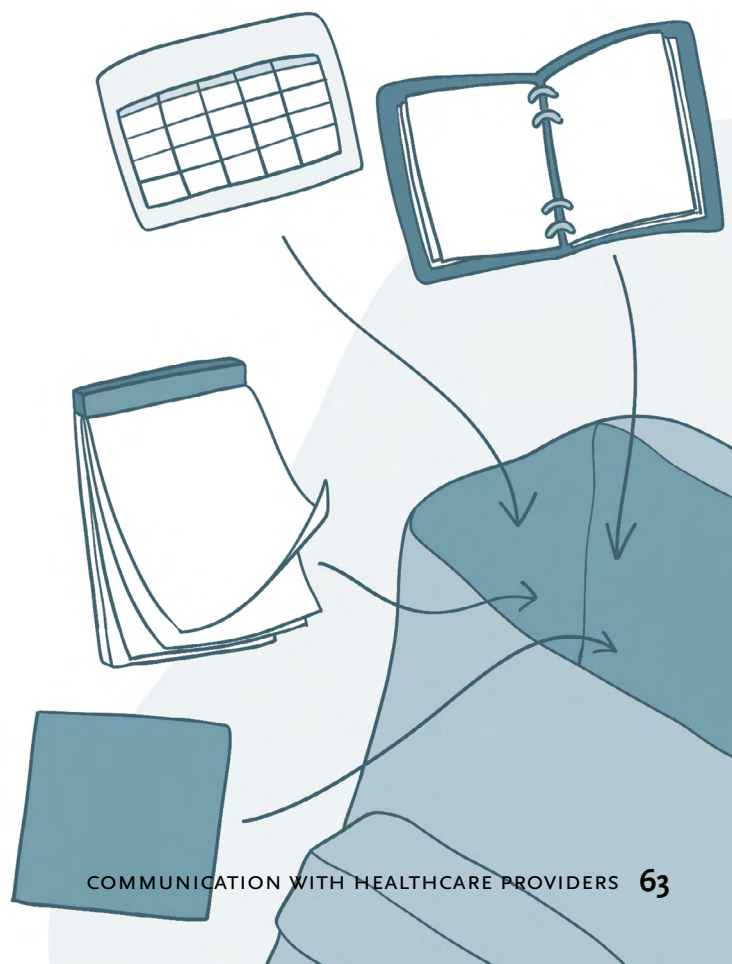
There is usually one person responsible for coordinating cancer care within the healthcare team.

This may be their general practitioner, their oncologist or palliative care physician, or a care coordinator. It is useful to know who is coordinating their care, so you have a main point of contact. You can ask anyone in your healthcare team, and they will be able to tell you who this person is.

If available, you could seek out a nurse navigator, patient advocate, or social worker if you are having trouble navigating the healthcare system. They can work with both of you and point you in the right direction.

Some final thoughts

It's helpful to remember that a healthcare team might not be able to meet all of your needs, all of the time. You may work hard to improve your relationship, but the actions and behaviours of the health care team is not your responsibility. In some cases, if the relationship is not satisfactory, you may be able to ask to switch providers, if this option is available.



Patients and Caregivers as Care Partners

In many healthcare systems, patients are encouraged to be involved as much as possible in making decisions about their care. This was not always the case, and in some places, it is not usual practice.

This approach has become more widely accepted over time. You might hear it referred to as "**shared decision making**."

The goals of shared decision making are to:

1. Fully inform patients about different treatment options and their risks and benefits.
2. Consider patients' values and preferences when making choices about various treatments.



In shared decision making, patients are encouraged to consider their own personal values and their quality of life. This is an important step towards making treatment goals with your healthcare team.

As a caregiver to someone with cancer, you may be involved in the decision making about their cancer care. Caregivers often play an important role in understanding the patient's wishes and values and advocating for them within the healthcare system.

Shared decision-making may seem like a simple idea, but it can be a complex process in practice. Here are some common difficulties:

- Patients and caregivers are required to learn a lot of new information in a short period of time
- Sometimes there is not a clear choice between the options being presented
- There can be disagreement between the treatment goals of the healthcare provider, the patient, and/or their loved ones
- These decisions come with a lot of uncertainty
- There is often a time pressure in making a decision

Even with the potential challenges, research has shown that increasing patient participation in decision making can improve health outcomes.

Shared Decision-Making

Take a moment to think about your experience with 'shared decision-making' and caregivers as partners in health care. Here are a few prompts and some space below to make notes if that's helpful to you.

Does your medical team involve you and the patient in decision-making? If so, what has this experience been like?

What is your role as the caregiver in the decision-making process?

What has the person you are caring for communicated to you about their goals and wishes?

What have you communicated to the person you are caring for about your goals and wishes for their care?

How do you see your role in facilitating communication with the healthcare team?

Omar's Story

Omar has metastatic lung cancer and has been managing his cancer with chemotherapy for the past two years. His oncologist recently told him that they have exhausted all standard treatments for his disease. His doctor told him about a clinical trial, which has potential benefits (i.e., extended survival) as well as side effects (i.e., worsening fatigue, nausea). The alternative option would be a watch-and-wait approach.



Factors in Shared Decision-Making

In a situation like Omar's, how would you order these factors impacting decision-making from least to most important (0=least important to 8=most important)? How do you think the person you are caring for would order these factors when making medical care decisions?

There is no right answer, just different opinions.

You	Factors	Them
	Quality of life	
	The opinion of the medical team	
	The opportunity to spend with family and friends	
	The opinion of family	
	The potential to contribute to medical science	
	My own opinion	
	The possibility of benefit from a clinical trial (i.e., extended survival)	
	The possibility of risks associated with a clinical trial (i.e., worsening fatigue, nausea)	

Shared Decision-Making

How do you make decisions?

What kind of information have you found helpful to make treatment decisions to date?

Do you both discuss these factors when making treatment decisions?

Are there other important factors that you consider which are not listed above?

Have you considered other sources that influence treatment decisions (e.g., friends, family, medical team, your own research)? How much weight do you give to their opinions?

Here are some common questions to consider in treatment decision-making. Reflect while answering these questions.

What do you hope from treatment?

What is the purpose of the treatment?

What are the possible risks of the treatment and how likely are they to occur?

Are the possible benefits from treatment greater than the possible risks?

Beliefs, Values and Decision-Making

A **belief** is an idea that a person (or group of people) accepts as being true. **Values** are ways of thinking about the world and our choices in terms of what is right and wrong, or positive and negative. Our society, culture, and our different social groups, can all influence our beliefs and values.

Our beliefs and values play an important role in decision-making. However, some people find it difficult to know what their preferences are. In Omar's case, he was having trouble making decisions because his family members were weighing possible outcomes differently based on different values. He wasn't sure which position he wanted to take or which course to pursue.

The following questions can help you reflect and think more about your own beliefs and values and the beliefs and values of the person you are caring for:

What do you consider “good quality of life”? What about the person you are caring for? Are the answers similar or quite different? How so?

What are your goals for treatment and care (e.g., to cure the cancer, trying all available options, maintaining quality of life, maintaining hope, providing pain or symptom relief, etc.)? Do both of you have the same goals of care?

Are these goals reflected in the current treatment plan?

The Caregiver Role

Caregivers play an important role throughout the cancer experience, including supporting the patient with medical decision-making.

It is common for patients and their family, friends and caregivers to have different beliefs and values and thus different opinions about what to do moving forward. It can be tricky to deal with these differences and there are no universal rules for the right way to resolve conflict about a patient's medical care. Some caregivers have strong opinions on what should be decided moving forward, where others may not know which direction to take. In general, it's important

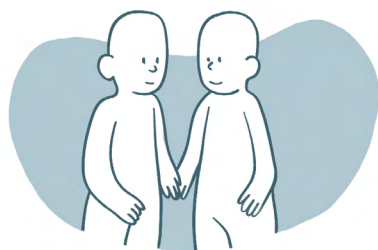
to recognize and understand your own needs and desires as a caregiver and separate those from the desires of the person you are providing care to.

While the patient is doing well and can make their own decisions, you may play a more collaborative role in decision making. However, as the disease advances and if they are no longer able to decide for themselves, you may become more involved in their decision-making. Thus, it's important to discuss and understand their wants and beliefs in advance so that you can make decisions that would best reflect their wishes.

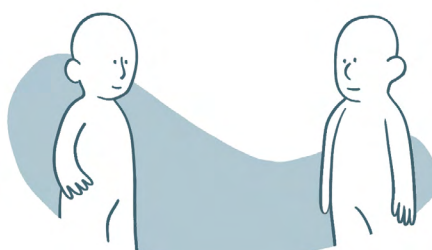
Your Style of Relating to Healthcare Providers

Recognizing our patterns can help us understand ourselves and others better. It can also help us make adjustments to work together more effectively.

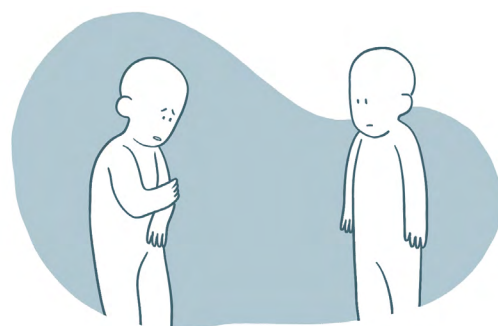
Here are some common patterns for relating to other people. Please keep in mind that these are simplified examples to help you think about your own tendencies in relationships. You may have different relationship patterns with different people, and your patterns may change over time and depending on the situation.



Some people tend to create intimate (close) relationships with others.



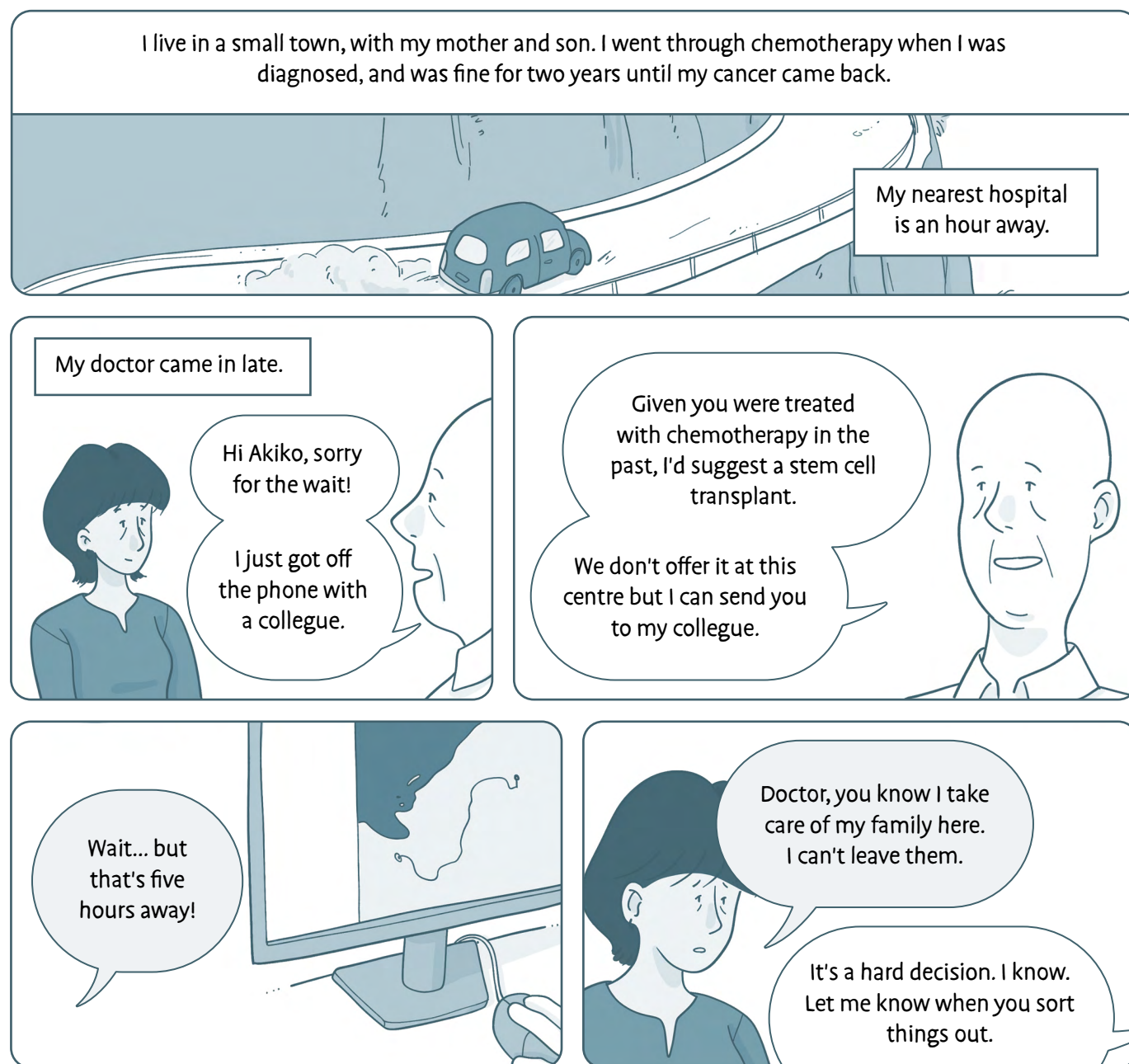
Some prefer more space and distance in their relationships.



Other people desire closeness but live with a great deal of anxiety about the solidity of their relationships.

Akiko's Story

Akiko is 49 years old and has Refractory Acute Myeloid Leukemia (AML). She is divorced and shares custody of her 12-year-old son with her ex-husband.



Notice how in the example above, Akiko felt dismissed by her oncologist, who may have been focused on her treatment without considering what this could mean for her. Akiko may feel scared about the possible side effects, how the treatment will affect her everyday life, how she'll be far from her loved ones and how that might burden them.

While communication with the healthcare provider may be focused on the cancer and treatment, this is also a human relationship. Patients and families may also have a need for emotional support and an understanding of the patient as a whole person and their broader situation.

Considering what you have read so far...

How do you think you and the person you are caring for relate to the healthcare team?

Do you feel that you can count on them during difficult times?

Do you worry about whether they will be there for you?

What do you think would improve this relationship?

Your Relationship with the Healthcare Team

Sometimes people will have transitions and different clinicians involved in their care at different times.

How have these transitions worked for you in the past? Have you felt that you've fallen through the cracks, unsupported, or neglected? Are you anticipating or worried about transitions in the future?

Do you feel like the healthcare team knows and understands both of you? Is there anything you wish that your healthcare team knew about you (e.g., background, specific needs or challenges, your current circumstances or stressors)?

Have you had past experiences with medical care that are shaping your current experiences?

Beyond your oncology team, do you have other healthcare providers (e.g., family healthcare team, naturopath, complimentary/ alternative healthcare providers) that are supporting you? Do you feel there is communication and collaboration between these providers?

There is a lot of information about cancer and cancer care available through the internet, social media, or other routes that is sometimes overwhelming or contradictory. How are you sorting through this information and making sense of it for yourself?

Summary of Domain 1: Communication with Healthcare Providers

Communication Challenges for Caregivers

Caregivers may...

- feel unsure about their right to ask questions or engage during appointments.
- have different information needs than the patient
- act as mediators between the patient and healthcare team, adding emotional and logistical complexity.
- The caregiver role changes — often from supportive to primary decision-maker, especially as an illness progresses.
- Balancing involvement and respect for the patient's autonomy can be challenging, especially when opinions differ.

Tips for Improving Communication

- **Be open and seek understating:** Share all concerns with the health care team and don't hesitate to ask questions or for clarification
- **Clarify and communicate preferences:** Let providers know how much information you want and how you prefer to receive it.
- **Be prepared:** bring a list of key questions to appointments and take notes, or request to record conversations (with permission).

- **Bring support:** if you are unable to attend an appointment have a trusted individual accompany the person you are caring for to the appointments.
- **Try to stay organized and connected:** Keep important info in one place, know who coordinates care, and ask how to reach providers between visits.

Shared Decision-Making

- **Goal:** that patient and caregiver are care partners, participating in decision-making that is fully informed and takes into account values and preferences.
- Shared decision-making may seem like a simple idea, but it can be a complex process in practice.

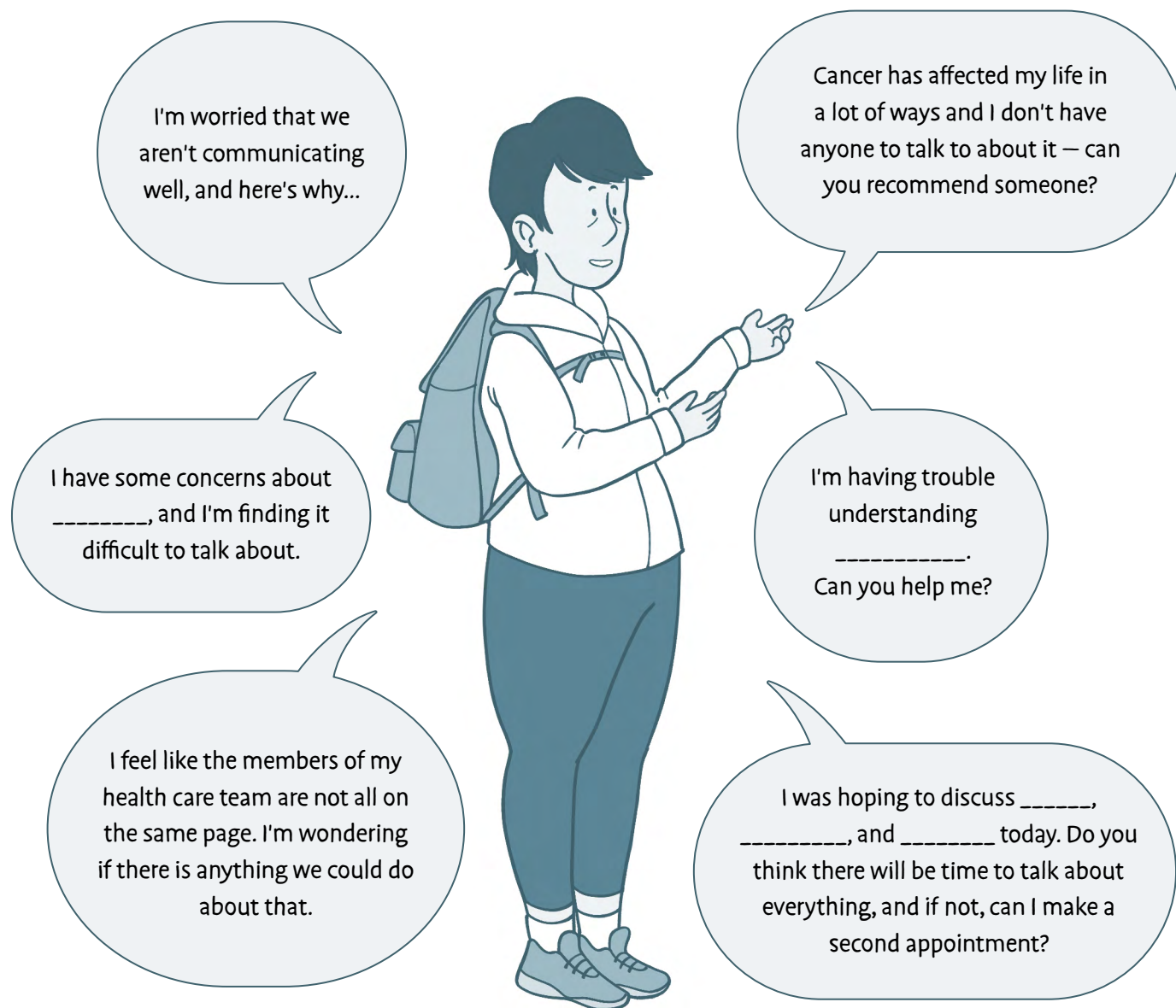
Here are some common difficulties:

- Information overload and time pressure can feel overwhelming for patients and caregivers especially when it comes time to make decisions.
- Uncertainty and lack of clear options can complicate treatment choices.
- Conflicting goals between patients, providers and caregivers may lead to disagreements during care planning.

Starters for Difficult Conversations

Important relationships take effort from both parties. Clear communication on your part may help facilitate better understanding and care from your team.

If you would like some suggestions on how to initiate discussion about communication difficulties, here are some prompts below. Some of these suggestions are from the American Cancer Society².



2. American Cancer Society. (2025). Cancer Research. Caregiver and Family. What a Cancer Caregiver Does. How to Communicate as a Caregivers How to Communicate as a Caregiver | Caregivers and Family | American Cancer Society <http://cancer.org/cancer/caregivers/what-a-caregiver-does/communication.html>



Pause and Consider

Pause for a moment. *How are you feeling?*

Consider what you need right now. *What might help to support you in the next few minutes, hours, or the coming days?*