

Preparing for Your Doctor's Visit

A Worksheet for Discussing Mental Health



Receiving a cancer diagnosis is difficult. That moment may feel overwhelming to you and your loved ones. It may cause you to feel anxious, angry, or worried. You may notice that these feelings impact things such as friendships or your ability to enjoy activities. It is normal to feel these emotions. You also may have a pre-existing mental health diagnosis that could worsen because of the added stress that cancer can bring. Your health care team and loved ones will ask how you are feeling. It is important to be open and honest with them.

Your mental health is just as important as your physical health. Mental health involves your emotional, mental, and social well-being. Mental health challenges can sometimes be diagnosed as a mental illness. This could be when they affect a person's thinking, feelings, behavior, or mood in a way that makes it difficult to accomplish their daily tasks. A mental illness is diagnosed by a medical provider specialized in treating mental health. This could be a licensed psychologist, counselor, or psychiatrist. When emotions like sadness or anxiety last for a long time and impact your daily life, you may be told that you have a mental illness. Even if you have not been diagnosed by a professional, you may struggle with similar feelings and can benefit from receiving

support. Remember, when you experience new or increasing mental health symptoms, consider seeking help. Seeking help early can give you the tools to problem-solve, prevent symptoms from worsening, and get to a better place.

Members of your health care team can help you maintain and improve your mental health and quality of life. You may be asked to complete a distress screen by a member of your health care team. A distress screen assesses your mental and emotional state and helps your care team know how to best support your needs. Again, it is important to answer these questions honestly so that you can get the support you need.

The following guide has been created to help you take control of your care. It will help you speak to your health care team about ways to support your mental health. It provides a quick overview of mental health, questions to ask your health care team, a worksheet to help set goals, and resources for information and support.

After a cancer diagnosis, things may happen quickly. It is normal to feel anxious, overwhelmed, or sad. There are many resources available to both you and your loved ones. Counseling, support groups, peer mentorship, and wellness programs are some

examples. You can learn more about coping and other details on our *Frankly Speaking About Cancer: Mental Health* webpage (www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns). You can also call our Cancer Support Helpline at 888-793-9355 to speak with a navigator for support and resource information that may be available to you. If you are having a mental health crisis, such as thoughts of harming yourself or are experiencing a mental health emergency, call 988 or go to your closest emergency room.

988 SUICIDE HELPLINE

This is the dialing code for the U.S. National Suicide Prevention Lifeline. Those in the U.S. can call, text, or chat 988 to connect with trained counselors. This is free and confidential support for those in suicidal crisis or emotional distress. Visit 988LifeLine.org for more information.

People in Canada can call the Suicide Prevention Service at 833-456-4566 or text 45645 between 4pm and midnight to connect with a crisis responder. These are free resources for mental health and crisis support.

GETTING TO KNOW YOUR HEALTH CARE TEAM

Cancer treatment is complicated and can change quickly with new discoveries. You need a care team you can trust to take the best care of you. This team should treat you as an equal partner in your care and encourage you to ask questions. It is important to find at least one person on your team that you feel most comfortable with when discussing mental health or seeking additional support. Your team may include several health care professionals who work together including:

Physicians, Oncologists, Nurses, Nurse Practitioners, Physician Assistants: You may see a **medical oncologist, surgical oncologist** and/or a **radiation oncologist** who specializes in your cancer type. Nurses, Nurse Practitioners (NPs), or Physician Assistants (PAs) may work with the oncologists and help answer questions about your cancer. These health care professionals are a great resource to speak with about your mental health. They can connect you with helpful supports such as social workers, counselors, psychiatrists, and more.

Patient or nurse navigator: Some cancer centers have patient navigators or nurse navigators. They can help you navigate the healthcare system, such as scheduling tests and appointments and providing education. They help patients and caregivers identify barriers to care and make connections to helpful resources.

Psychiatrist: A psychiatrist can play an important role in helping you manage mental health concerns, including those related to cancer or cancer treatment. These professionals can diagnose a mental illness and recommend and prescribe medications or other supportive care therapies. These therapies manage and support your mental health without interfering with your cancer treatment.

Psychologist: This is a trained health professional who can diagnose a mental illness, help to address emotions, and teach you how to cope with life's challenges. You may choose to meet with them one-on-one or in a group setting. Consider finding a psychologist that specializes in oncology.

Social worker: This person helps you and your loved ones find resources to cope with cancer and its treatment. They can navigate the costs of care and offer assistance with



other practical concerns. They may also be helpful when trying to find ways to help you with your mental health. Some social workers are also qualified to provide one-on-one or group counseling.

Therapist/Counselor: Someone who specializes in helping patients and families resolve their concerns about their mental health. Many therapists specialize in helping with the needs of people living with cancer and their caregivers. They can be found working in a hospital, cancer center, or at an outside clinic or private practice.

Clergy or Chaplain: This person helps with spiritual and mental well-being. They may be based in the hospital where you are receiving treatment, or you may seek support from a clergy member in your community. They provide spiritual care and support.

MENTAL HEALTH AND CANCER SURVIVORSHIP

Experiencing cancer as a patient or caregiver can impact your mental health even after treatment ends. Cancer survivorship

describes the time when all active treatment has been completed. You may or may not take additional medications to help with side effects or prevent the cancer from coming back. Similar to when you first learned about your cancer diagnosis, the survivorship phase can bring on challenging emotions that may impact your well-being. During this time, cancer survivors typically have fewer appointments with their health care team. This can be a difficult transition and may cause some increased stress or fear of recurrence. You may also experience some lasting emotions of anxiety or stress because of your cancer treatment experience. You may find that you were so busy during treatment that you did not have time to process your emotions. It can be overwhelming making the transition into this new phase. All of these emotions are normal. It remains important to connect with your primary care team or cancer care team when you notice emotions impacting your quality of life.

CANCER SUPPORT COMMUNITY HELPLINE

In need of support? CSC can help! Contact the navigators on the Cancer Support Helpline® if you are...

- Feeling sad, depressed, scared, frustrated, or isolated.
- In need of someone to listen and help you process.
- Looking for support groups or peer support.
- Considering finding a therapist and don't know where to start.
- Experiencing financial distress and needing support or resources.
- Having trouble communicating—with providers, caregivers, friends, family, employers, and more.
- Living with or beyond cancer and wanting help navigating what's ahead.

Call **888-793-9355** for resources and support.



TALKING ABOUT MENTAL HEALTH

You will hear many words used to describe mental health and its components. It can be helpful to know some terms as you discuss this topic with your health care team. It is okay if your feelings are changing and do not perfectly match one of these terms.

MENTAL WELL-BEING: When you are aware of how situations can affect your mental, emotional, and social health. Mental well-being involves learning and using strategies to prevent or cope with mental health challenges.

ANXIETY: A feeling of uneasiness, worry, or fear that occurs because of stress. Anxiety can present with a racing heartbeat, tense feelings in your body, and more.

SCANXIETY: The uncertainty of waiting for test results, such as from a scan or bloodwork. This may be related to worry that a disease such as cancer has spread or come back.

STRESS: The body's reaction to pressure, such as certain worrisome events, trauma, or illness. Stress can cause both physical and emotional sensations or symptoms. Everyone responds to stress differently.

DISTRESS: An unpleasant state that affects how you feel, think, and act. Distress can cause different emotions such as fear, sadness, anger, or worry.

GRIEF: The emotional response to a loss. This could be loss of a person, identity, or control.

DEPRESSION: A diagnosed mental illness. It causes a persistent feeling of sadness or loss of interest in things you once enjoyed.

SUICIDAL IDEATION: Thoughts or ideas about death and suicide.

SUICIDALITY: The risk of suicide, usually indicated by serious suicidal ideation that leads to a plan or intentions to act on suicidal thoughts.

MENTAL ILLNESS: A set of diagnosed conditions that affect your mood, thinking, and behavior.

TIPS FOR MANAGING YOUR MENTAL HEALTH

- Talk with your doctor and confirm that the specialists on your health care team have experience assisting cancer patients with their mental health.
- Take a loved one or friend with you to appointments, for support and an extra set of eyes and ears. Ask your doctor how your caregiver can receive support while you are completing treatment.
- Talk to a therapist or psychologist who specializes in cancer about your feelings and their recommended ways to cope with the impact that cancer has on your mental health. A social worker could also direct you to appropriate resources for you and/or your caregiver.
- Focusing on your physical health can have a beneficial impact on your mental health. Consider going for a walk regularly or taking classes, such as yoga or meditation.
- Keep a journal as a way to describe and release your feelings. Join a support group or speak with a family member or friend about how you are feeling.
- Pay attention to when you experience feelings of sadness, fear, frustration, nervousness, or worry.



Below are some symptoms and side effects people may experience during cancer treatment, as shared by members of our Cancer Experience Registry. Think about how often they affect you. Talk to your health care team about how best to manage them if you respond with “Sometimes” or “All the Time.”

	Rarely	Sometimes	All the Time
Feeling too tired to do the things you need or want to do			
Fear of disease progression			
Feeling lonely or isolated			
Feeling irritable or overwhelmed			
Pain and/or physical discomfort			
Health insurance or financial concerns			
Sleep problems			
Feeling nervous, anxious or afraid			
Feeling sad or depressed			
Worrying about family, children, and/or friends			
Other:			

THINK ABOUT TREATMENT AND YOUR PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of each treatment and how each treatment might affect the goals that you have for your life. Possible goals may be to live as long and as well as possible, contribute to progress in science by taking part in research, make it

to a special event/milestone, or find cutting edge treatments that are available to you. Let your health care team know about your treatment and personal goals. Remember that your goals may change over time. A counselor or mental health professional can help you to discuss and plan for these goals.



SETTING YOUR PERSONAL GOALS FOR TREATMENT

Physical Health and Mental Health and Well-Being	<i>What is most important for you to be able to do and feel?</i>
Family and Social Relationships	<i>What is going on in the lives of others that is important to you?</i>
Work/School	<i>Do you want or need to continue working? Can you adjust your schedule or responsibilities?</i>
Social Support/Community Involvement	<i>Are you getting the support you need from your loved ones and your community? Are you able to stay active/involved in your community?</i>
Other:	<i>What else is important to you?</i>

MENTAL HEALTH SUPPORT TYPES

There are many resources available to help you manage and improve your mental health. This is not a “one size fits all” model. If one does not work for you, don’t give up. There is beneficial support out there for everyone. These options may be offered within your care center or at an outside provider. Speak to your care team about what is available.

One-on-One Therapy: Meeting with a licensed therapist, psychologist, or counselor to discuss any concerns. Sessions typically last 60 minutes and can be done in-person or virtually.

Group Therapy: Group therapy is usually led by a professional such as a therapist or psychologist. Everyone in the group has similar needs and can benefit from each other’s support.

Support Group: These groups offer peer support or ways to cope from others in similar situations. This can be led by a clinician or other facilitator.

Helpline/Hotline Assistance: Typically associated with support organizations. Calling a helpline can give you additional resources appropriate for you and in your area.

Refer to the end of this guide for a list of trusted organizations. CSC and other organizations have helplines, support groups, and other resources to assist you and your loved ones.



QUESTIONS TO ASK YOUR HEALTH CARE TEAM

If you are feeling either better or worse today than at your last appointment, let your health care team know. Write down your questions before each doctor's visit. Below are some suggested questions and discussion points. Concentrate on the issues that are most important to you.

My top goals for treatment are: [fill in your answers from page 6].

What can I do to make sure I am mentally healthy before, during, and after cancer treatment?

Are there any mental health resources or professionals that I can utilize within the same location that I am receiving my cancer treatment? How do I get in contact with them?

What should I expect or watch for regarding difficulties with my mental health? What mental health resources are available to me?

What should my caregiver expect or watch for regarding difficulties with their mental health? What mental health resources are available to them?

What mental health symptoms or challenges are commonly seen with the treatments that I am receiving?

Who do I speak to when I am experiencing anxiety, stress, or other mental health emotions? How do I get in contact with them?

MENTAL HEALTH INFORMATION AND SUPPORT

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Cancer Support Community · 1-888-793-9355 · www.CancerSupportCommunity.org

National Alliance on Mental Illness · 1-800-950-NAMI (6264) · NAMI.org/Help

American Cancer Society · 800-227-2345 · www.Cancer.org

MentalHealth.gov · www.MentalHealth.gov

National Alliance for Caregiving · www.Caregiving.org

National Cancer Institute · www.Cancer.gov/About-Cancer/Coping/Feelings

National Suicide Prevention Hotline (U.S.) · 800-273-8255 or 988 (text or call)

Canadian Mental Health Resources:

Suicide Prevention Service (Canada) · 833-456-4566 or text 45645

Hope for Wellness Helpline - Canada · 1-855-242-3310 · www.HopeforWellness.ca

Wellness Together Canada · text WELLNESS to 741741 for immediate crisis support

www.WellnessTogether.ca



CANCER SUPPORT COMMUNITY RESOURCES

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Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 190 locations, CSC and Gilda's Club network partners provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Become-Advocate.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns. For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org

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