

TREATMENT INFORMATION SERIES

Emotional wellness

Coping with distress, anxiety, depression, and grief

CHORDOMA FOUNDATION

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The Chordoma Foundation is committed to helping patients and caregivers make the most informed treatment decisions. We created the *Treatment Information Series* to provide you with in-depth information about each aspect of treatment that may be involved in your chordoma journey. The complete series, as well as other materials for patients and caregivers, is available at **chordoma.org/educational-materials**.



Understanding mental and emotional health

A diagnosis of a rare cancer like chordoma does not just affect your body. Learning you have chordoma, managing treatment, and dealing with physical side effects can also affect your mind, bringing up many feelings and emotions. Some might be familiar feelings, while others might be new or confusing. **Whether you're currently in treatment, finished with treatment, or supporting a loved one with chordoma, it is normal to experience feelings such as anxiety, fear, depression, and grief.**

Just as you would seek support to address any physical challenges related to chordoma, it is also important to care for your mental and emotional health. There are ways to manage your feelings and support emotional wellness throughout your journey, and **you don't have to do it alone**.

This booklet will help you:

- **Understand mental and emotional health** and the impact they have on your overall health
- **Recognize and acknowledge your emotions**
- **Talk with your doctor** about what you're experiencing
- **Learn strategies** for managing distress and other emotions
- **Get help and support** to improve your emotional wellness



Mental health includes emotional, psychological, and social well-being. A person's mental health affects how they feel, think, and act and helps determine how well they handle stress, relate to others, and make choices.

Emotional health is one aspect of mental health. When a person is emotionally well, they are aware of their emotions and can manage and express both positive and negative emotions accordingly.

Being aware of how you're feeling starts with knowing how to recognize and identify your emotions. Doing so can help you see the impact your emotions have on your overall health and find ways to regulate and manage them.

Stress, distress, and accompanying emotions

The emotions we experience are often the result of some kind of stress, either positive or negative, in our lives. **Stress** is a normal response to life events, but it can also cause mental and emotional health challenges. Stress can be "good stress", which is often short-term and is related to more positive life events like moving to a new home or starting a new job. Stress can also be longer-term and more severe, such as dealing with food or housing insecurity, the passing of a loved one, or managing a health issue like cancer.

Distress occurs when any type of stress exceeds a person's ability to manage it, causing sorrow, pain, anxiety, fear, and more. It is common for people with cancer and their caregivers to experience distress at some point during their journey with cancer. When this happens, some of the most common emotions that follow include:

- **Anxiety**: Feelings of fear, dread, and uneasiness. Anxiety is sometimes described as a type of fear that has to do with something going wrong in the future rather than right now. It can cause sweating, restlessness, tension, and rapid heartbeat.
- **Anger**: An emotional state that can range from feelings of mild irritation to intense fury and rage. It can have physical effects such as increasing your heart rate, blood pressure, and adrenaline. Anger can be a good thing if it prompts you to express negative feelings in a healthy way or motivates you to find solutions to problems. However, it can also make it difficult to think clearly or make you want to cause harm to something or someone.
- **Depression**: Ongoing feelings of sadness, despair, loss of energy, and difficulty dealing with everyday life. Other symptoms of depression include feelings of worthlessness and hopelessness, loss of pleasure in activities, changes in eating or sleeping habits, and thoughts of death. Different from ordinary sadness, which comes and goes, clinical depression doesn't go away easily and can affect all aspects of life.

- **Fear**: One of the most powerful and automatic emotions. Fear is caused by the anticipation or awareness of danger. After treatment ends, one of the most common concerns survivors have is that their chordoma will come back. The fear of recurrence is very real and entirely normal. Signs of fear may include increased heart rate, faster breathing or shortness of breath, sweating, chills, and upset stomach.
- **Grief**: Deep sadness and sorrow in response to a significant loss. Grief is often related to the death of a loved one, but it can also be the result of experiences such as the loss of identity or physical function from a serious, long-term illness. It may include feelings of great sadness, anger, guilt, and despair. Physical symptoms, such as not being able to sleep and changes in appetite, may also be part of grief.



Loneliness

Being diagnosed with a rare disease like chordoma often causes unwelcome feelings of isolation, lack or loss of companionship, or inability to identify with others. Sometimes, these feelings of loneliness can escalate into anxiety, depression, fear, or grief. If you notice a growing sense of uneasiness from being (or feeling) alone or cut off from others and this persists or worsens over time, take note and seek help.



Mental and emotional health during the cancer journey

There is evidence that people who have been diagnosed with cancer are more likely than the general population to experience mental and emotional health challenges.[1,2] Being diagnosed with and managing a life-changing disease can cause unwanted or overwhelming distress that interferes with quality of life. While some stress is normal, remaining in a heightened state of distress for long periods of time can negatively impact your physical health and wellbeing. Fear of disease recurrence, alteration of identity, and perceived (or actual) loss of connection with friends and family can make this already challenging situation feel even harder.

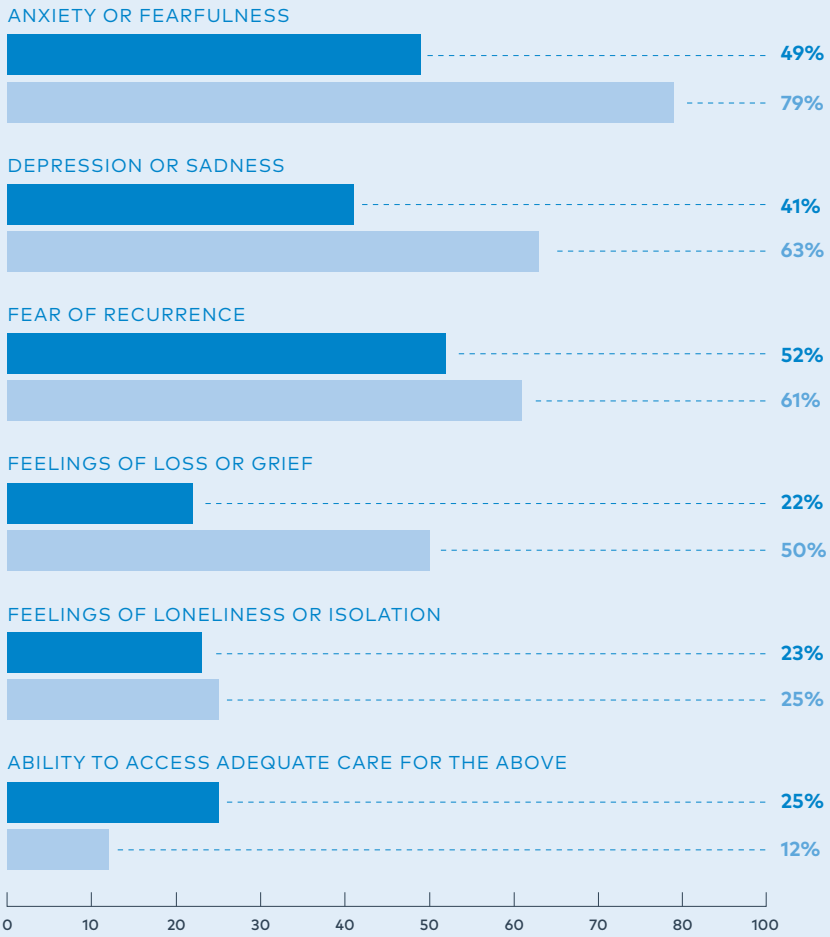
The Chordoma Survivorship Survey, completed in 2021, found that it is common for chordoma patients and survivors to experience a range of emotions such as anxiety, fear, depression, and sadness, both during and after treatment. The survey also found that several of these emotions are even more common among co-survivors, which includes spouses, partners, parents, family members, and friends. Yet, the survey also found that, despite how often they're experienced, few people access adequate care for these challenges.

The co-survivor experience

Caring for someone with cancer — whether you're the main caregiver or a supportive family member or friend — often brings with it emotional distress that can feel overwhelming. It's important for co-survivors to be aware of how their emotional and mental health are being impacted and get support when needed.

See "Managing emotional distress: *Caregivers and co-survivors*" on p. 30 for more information.

Chordoma Survivorship Survey: Mental and emotional health



Patient and survivor percentages in this chart represent an average of the survey responses received across all tumor locations (skull base, mobile spine, and sacral)

See more results from the Chordoma Survivorship Survey at **chordoma.org/survey-results**

Post-traumatic stress and cancer

Research has shown that **post-traumatic stress disorder (PTSD)** is more common in cancer survivors than in the general population.[3]

Following any distressing or traumatic event, it is common and normal to experience fear, feel anxious, have bad dreams, or avoid situations that remind you of the traumatic event.

Most of the time, these symptoms go away after a few days or weeks. If they do not, they can begin to severely impact everyday life and lead to PTSD, which is a clinical diagnosis recognized by doctors and mental health professionals around the world.

PTSD is historically associated with experiences like war, natural disasters, violence, abuse, or serious accidents, but more recently, mental health professionals have recognized that other life events, such as dealing with cancer, can cause PTSD, too. Receiving a cancer diagnosis, undergoing treatment, dealing with side effects, and facing repeated tests and imaging are aspects of a cancer journey that can cause trauma-related symptoms and lead to PTSD.

Sometimes, people who experience trauma undergo a kind of transformation afterwards, developing a new understanding of themselves and the world they live in. **Post-traumatic growth (PTG)** is the concept that people often see positive growth after dealing with adversity and stress. For instance, cancer survivors and their families sometimes say that following diagnosis and treatment, they appreciate little things in life more and have a more positive outlook.

If you think you are experiencing symptoms of PTSD, talk with your doctor or mental health care provider.



Causes of emotional distress

Both during and after chordoma treatment, it is normal to experience stress related to all the life changes you are going through. When you first learn that you have chordoma, you may feel like your life is out of control. Doctor visits and treatments disrupt your normal routine. People use medical terms that you don't understand. You might not be able to do the things you enjoy. And the effects that chordoma and its treatments have on your body can make these feelings worse.

Factors that increase the risk of normal, expected stress causing emotional distress are often related to chordoma, but other aspects of life can contribute as well. These factors include:

- Age
- Stage of disease (new diagnosis, recurrence, advanced or metastatic disease)
- Side effects of treatment (such as fatigue, pain, functional deficits)
- Financial difficulties
- Health insurance status
- Lack of access to care from providers experienced in treating chordoma
- Little to no connection with other chordoma patients or caregivers
- Changes in relationships with family and friends
- Inability to work or go to school
- Unmet social or spiritual needs
- Depression, anxiety, or other emotional challenges that were present before diagnosis

Doctors and researchers have studied the connection between our brains and our emotions since the earliest days of science. We now understand that an experience can prompt the brain to send signals through the body that automatically and unconsciously create physical reactions. These physical sensations instantly send messages back to the brain that it interprets and records. Those interpretations and recordings are what prompt our experience of having emotions. Here's a possible scenario:



The field of neuroscience has made great progress studying the connection between our brains and our emotions, and there is still a lot to be learned. Research has found that our individual brain chemistry plays a key role in how we each process and communicate emotions. What causes one person great emotional distress may be manageable for someone else. **What we do know is that our emotions are not faults or weaknesses, but rather a result of the communication between our bodies and our brains.**

Distress and survivorship



The successful completion of active treatment is an important and exciting milestone for anyone who has dealt with chordoma. The resulting transition to survivorship usually means fewer medical visits and less direct support from the medical team that rallied around you during treatment. There are often expectations (yours or others) that you should be celebrating or relieved that treatment is complete and ready to return to "normal life".

However, the shift to managing the physical and emotional ups and downs of life as a "survivor" is experienced differently by each person. For some, **this transition can sometimes cause feelings of distress to intensify**. If you notice this happening to you, talk to your care team and ask about support and treatment options.



Impacts of emotional distress

Although the mind and body are often viewed as being separate, **mental and physical health are closely related**. Good mental health can positively affect your physical health. In return, poor mental health can negatively affect your physical health.

Research has found links between chronic mental and emotional stress and immune function, with greater distress contributing to less effective immune responses.[4,5] Too many stress hormones increase inflammation in the body, which hinders the immune system. A weakened immune system can make it easier for cancer cells to grow and harder for them to die.

Emotional distress can have serious impacts on your everyday life, as well. You may find it more difficult to concentrate on work or school, to interact with people socially, participate in activities you normally enjoy, or take care of yourself and your family.

When to seek help

If feelings of distress, anxiety, depression, or fear consistently last for more than a few weeks or begin to affect most aspects of life, making it hard to function or cope, it is important to seek help.

The emotional, social, spiritual, and physical impacts of chordoma affect you in different ways at different times, so it's important to take the time to ask yourself questions such as:

- What feelings am I aware of having right now?
- Which of these feelings is the strongest?
- When did I start feeling this way?
- How are these feelings impacting my thoughts and actions?

Most of us rarely stop to check in with ourselves in this way. We tend to think of things more generally: *I'm in a good/bad mood today, or I've got so much to do and don't feel like being social right now.* But we don't recognize the emotions behind these thoughts. It's also common to feel pressure to put on a good face or appear strong for others while dealing with chordoma. But doing so can lead to feeling even more lonely or isolated.

Pause for a few moments throughout every day to ask yourself questions like those listed above. This can help you name and track your emotions, making it easier to see patterns that indicate the difference between ordinary emotional ups and downs and more serious emotional distress.

As soon as you notice your emotions beginning to interfere with your ability to function, even if you think your feelings or thoughts are minor, talk to your care team about what you're experiencing.

Remember that your care team is treating YOU, not just your chordoma, and they count on you to tell them how you're feeling. While it may be difficult to talk about your emotions, you're not alone. **It's okay — and important — to ask for help.**

Signs that you should seek help include:

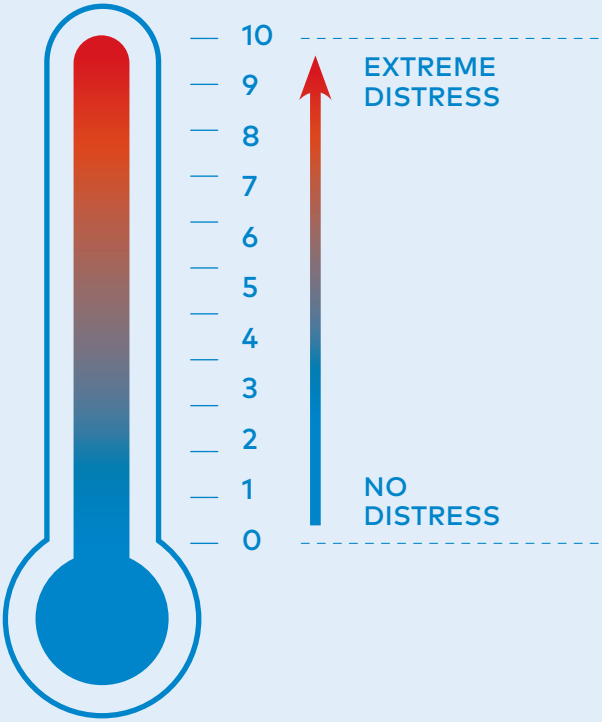
- Your feelings don't lessen or go away
- Your feelings keep you from doing normal activities and interfere with your ability to function
- You are constantly overwhelmed or to the point of panic
- You don't enjoy doing things the way you used to
- You are having suicidal thoughts

Getting help for suicidal thoughts



Suicidal thoughts are thoughts that life isn't worth living or when you're thinking about or planning to harm or kill yourself. This is a very serious symptom of clinical depression that you should never keep secret. Tell a family member, friend, or your doctor immediately if you're experiencing these thoughts.

If you feel you're in crisis and cannot reach your doctor or a loved one, call the U.S. National Suicide Prevention Lifeline at +1 (800) 273-8255 or visit the International Association for Suicide Prevention at findahelpline.com for helplines in other countries.



Distress screening

Nurses, oncology social workers, and patient navigators may conduct periodic distress screenings at appointments during and after your treatment. They may use a questionnaire or a 0 to 10 scale, similar to the way they ask patients to report pain.

A standard scale used by many cancer care teams is the **Distress Thermometer**, which is usually accompanied by a checklist of possible issues, to reflect how much and what kind of distress you feel today and how much you felt over the past week. Your doctor or care team will then work with you to determine the right support to meet your needs. But **you don't have to wait for a distress screening to ask for help**. You should contact your care team at anytime to discuss any distress you may be feeling.



Managing emotional distress: *Patients and survivors*

Emotional distress associated with chordoma is common and manageable. Keeping your care team informed about your emotional experience will help them connect you to the right support services so you can concentrate on getting, and staying, well. These may include medication, mental health services such as counseling and support groups, relaxation therapies, creative therapies, or some combination thereof.

The American Cancer Society offers some suggestions on do's and don'ts for managing distress[6], including:

DO:

- **Rely on ways of coping that have helped you solve problems and crises in the past**, whether it's meditation, therapy, exercise, listening to music, or something else.
- **Deal with cancer one day at a time**, focusing as much as possible on getting the most out of each day in spite of your illness.
- **Use support and self-help groups if they make you feel better**, but leave any group or social situation that makes you feel worse.
- **Find a doctor who lets you ask all your questions**, and make sure there's a feeling of mutual respect and trust.
- **Explore spiritual and religious beliefs and practices** that may have helped you in the past.
- **Keep personal records** of your dates of treatments, lab values, x-rays, scans, symptoms, side effects, medicines, general medical status, and your doctors' contact information.
- **Keep a journal** if you need to express yourself without holding back. Journaling can be a very powerful tool.

DON'T:

- **Feel guilty** if you can't keep a positive attitude all the time. Low periods will come, no matter how great you are at coping. But if they become frequent or severe, get help.
- **Suffer in silence** or try to go it alone. Get support from your family, loved ones, friends, doctor, clergy, or those you meet in support groups who understand what you're going through.
- **Be embarrassed or ashamed to get help** from a mental health expert for anxiety or depression that disrupts your life.
- **Keep your worries or symptoms (physical or psychological) secret** from the people closest to you.



Noticing and practicing gratitude

On the other end of the emotional spectrum, confronting chordoma has been known to inspire feelings of **hope** and **gratitude**. Some people view their chordoma as a "wake-up call" and take from it the ability to notice and appreciate the little things in life, like spending time with friends and family, enjoying nature, or mending broken relationships.

But for others, hope and gratitude must be cultivated and practiced intentionally. This doesn't mean you have to ignore difficulties or force yourself to be positive and upbeat all the time. Instead, try to think about what you're experiencing from different viewpoints, focus on caring for yourself, or celebrate little victories along the way. Practicing gratitude can play a key role in developing healthy ways to cope in times of stress.



BENEFITS OF GRATITUDE

- **Increase resilience** in the face of stress and crisis
- **Open doors** to new opportunities and experiences
- **Lower perceptions of pain**
- **Impact physical responses**, including decreasing blood pressure, increasing immunity, and reducing stress, which may lower the risk of health complications associated with chordoma
- **Inspire other healthy behaviors**, such as regular exercise
- **Contribute to more satisfying relationships** with friends, family, and our respective communities

WAYS TO PRACTICE GRATITUDE

- **Keep a gratitude journal** to write down what you're grateful for (daily or weekly).
- **Select a gratitude reminder object**, such as an item or keepsake you can see or touch every day that makes you feel happy and can redirect you towards gratitude. Focus on this item during difficult times.
- **Write a gratitude letter** to someone who has had an impact on you. Use the opportunity to express your appreciation for how this person's actions have affected you.
- **Take gratitude walks** outside whenever you can. Try to notice as many positive aspects of your surroundings as you can. For instance, the warm feeling of sunshine on your skin, the enjoyment of a crisp breeze and changing leaves, or the smell of flowers in bloom.
- **Practice situation reframing** by taking a negative situation and trying to identify any positive aspects or benefits that have resulted from it.

Treatment, support, and resources

The following resources can help you manage distress and support your overall emotional health.



Individual counseling and support groups

Mental health professionals are trained to evaluate and treat all types of emotional distress and mental health challenges using a range of counseling approaches, including individual or group therapy. Support groups can also help ease feelings of distress by connecting you with others who have shared experiences and to community resources. Whether your feelings of distress are moderate or severe, mental health professionals can help you understand and cope with them.

Learn more about our support groups at **chordoma.org/groups**



Relaxation, meditation, and creative therapies

Activities that help you relax often help ease some forms of distress. These might include relaxation exercises, mindfulness, meditation, massage, and guided imagery. Creative therapies like art, dance, and music have also been shown to be helpful for people in stressful situations.



Exercise

Exercise is not only safe for most people during and after chordoma treatment, but it can also help you feel better. Moderate exercise has been shown to help with tiredness, anxiety, muscle strength, and heart and blood vessel fitness. Even light exercise, such as yoga, walking, or stretching can be helpful in staying as healthy as possible. Talk with your doctor before you start so you can make an exercise plan that's safe for you.



Medication

Sometimes medicine is needed to reduce distress related to chordoma, or counter the emotional health symptoms caused by treatment. Medications for depression and anxiety are prescribed by psychiatrists and some general practitioners, and are usually taken while a person is receiving some type of counseling to support them as well.



Spiritual support

In a time of crisis, many people prefer to talk with a person from their spiritual or religious group. Today, many clergy are trained in counseling people with cancer. They're often available to cancer care teams and will see patients who don't have their own clergy or religious counselor. Churches often offer faith-based support groups as well.



Social services

Having chordoma can affect your day-to-day needs. There are common, practical problems that a Chordoma Foundation Patient Navigator or an oncology social worker can help you and your loved ones address. Some practical challenges they can help you navigate include transportation needs, financial concerns, job or school concerns, help with daily activities, and cultural or language differences.



Contact a Chordoma Foundation Patient Navigator at **chordoma.org/request-help**





Finding care

Everyone affected by chordoma deserves to feel connected to someone who understands the experience and can help process the emotions that come with it. Asking for and accepting help from others is an important part of coping with emotional distress. There are lots of ways to find and get help.

Ask your doctor for a referral to a licensed counselor or mental health specialist, or seek one out yourself. These professionals include:

- **Psychiatrists**: Medical doctors who specialize in diagnosing and treating mental health problems. They can provide counseling as well as prescribe medication.
- **Psychologists**: Specialists with a PhD or PsyD doctoral degree who are trained to diagnose mental health disorders, provide treatment and counseling, and conduct research. Psychologists cannot prescribe medication because they are not medical doctors.

- **Licensed clinical social workers**: Specialists with a Master's degree in social work and advanced training in counseling who can also help with practical concerns, such as managing your health insurance and connecting you with local support groups.
- **Oncology social workers**: Specialists with a Master's degree in social work who provide counseling, education, and referrals specifically for people with cancer and their families.
- **Psychiatric nurse practitioners**: Registered nurses who have a Master's degree in mental health nursing, treat mental health conditions, and provide counseling. Like psychiatrists, psychiatric nurse practitioners can prescribe medication.
- **Licensed counselors**: Specialists with a Master's degree in counseling. They may also be called licensed mental health counselors.
- **Licensed pastoral counselors**: Specialists who have a Master's degree in ministry or divinity. They provide counseling from a religious or spiritual point of view.

Use online directory tools to find a mental health specialist anywhere in the world, such as:

- PsychologyToday.com/intl/counsellors
- OnlineTherapy.com
- InternationalTherapistDirectory.com

Explore mental health and meditation apps from the comfort of your home using a smartphone or tablet.

Contact the resource center at your local cancer treatment center to ask about classes, social support, and counseling options near you. Cancer support organizations, whether local or national, can also provide support and guidance.



Talking to a counselor can help you:

- Learn how to cope with your diagnosis
- Manage anxiety, depression, fear, and grief
- Feel less overwhelmed and more in control
- Cope with symptoms and side effects, such as pain and fatigue
- Deal with emotional concerns about self-image, body image, or intimacy
- Manage fears or worries about the future

Managing emotional distress: *Caregivers and co-survivors*

One of the most important — but often overlooked — tasks for caregivers is caring for themselves. A caregiver's physical, emotional, and mental health is vital to the wellbeing of the person who has chordoma.

As a caregiver, you may experience periods of stress, anxiety, grief, depression, frustration, and more. These are all common emotions for caregivers to have, and **you don't have to deal with them alone**. Talking with other people who are caring for a family member or friend with chordoma can help you cope. So can talking with a licensed counselor individually or as part of a support group. Oncology social workers, cancer resource centers, and your own general practitioner can help you find local support networks and resources in your area.

Some strategies for coping include:

- **Recognizing the signs of stress.** It may be time to seek help if you are feeling exhausted all the time, getting sick more than usual, having trouble sleeping, feeling impatient, irritated, or forgetful, not enjoying things you used to enjoy, or withdrawing from people.
- **Accepting help from loved ones.** Family, friends, and members of religious and community groups are often willing to assist with caregiving, chores, errands, or childcare. Accept their help and give them specific tasks. Consider making a list of family, friends, neighbors, and local organizations who can help and what tasks they are available to do.

- **Making time for yourself and other relationships.** Spending time doing something you enjoy, with someone whose company you enjoy, can give you a much-needed mental and emotional break. Those supportive relationships are important for your own health and well-being.
- **Learning about family and medical leave.** There may be programs available to you through your employer or government that provide time off to care for a seriously ill family member.
- **Being kind and patient with yourself.** Many caregivers experience occasional bouts of anger or frustration. And then they feel guilty for having these feelings. Try to find positive ways to cope with these difficult feelings. This could include talking with supportive friends, exercising, or journaling.
- **Taking care of your body.** Make time to exercise, eat healthy foods, stay hydrated, and get enough sleep. Also, re-evaluate your own health. The stress of caregiving can lead some people to develop or increase unhealthy habits, such as smoking, drinking too much alcohol, or using prescription medicine improperly. If you cannot make healthy changes on your own, seek professional help.
- **Watching for signs of depression or anxiety, and seek professional help if they persist.** Several studies have shown that caregivers are at an increased risk for depression and anxiety. Our own Chordoma Survivorship Survey found that caregivers report emotional health challenges at a higher rate than patients. If you are having trouble coping with your emotions and it lasts more than a few weeks, talk with your doctor or a licensed counselor.



How we can help

The Chordoma Foundation Patient Navigation Service is here to help. Our dedicated Patient Navigators are available to:

- Answer questions about chordoma and quality of life challenges
- Provide information on treatment, both for chordoma and common quality of life needs
- Identify and provide information on clinical trials open to chordoma patients, and other options for systemic therapy
- Give information about programs and organizations that offer travel and lodging assistance, co-pay relief, and other benefits
- Support requests and appeals to insurance companies
- Connect you with others in the chordoma community



Learn more about our Patient Navigation Service at **chordoma.org/request-help**

Learn more

Visit the Chordoma Foundation's website at **chordoma.org** for more information on chordoma, including research updates, the latest news on treatments, and ways to get involved.

Get help from a Chordoma Foundation Patient Navigator at **chordoma.org/request-help** or by calling +1 (888) 502-6109.

Connect with other patients and caregivers through the Chordoma Connections online community at **community.chordoma.org**.

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Important note about this publication

This content was developed by the Chordoma Foundation. It is not meant to take the place of medical or professional advice. You should always talk with your health and mental health care providers about treatment options and decisions.

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