



**COLORADO**  
**PALLIATIVE CARE GUIDE:**  
**SUPPORT** FOR PEOPLE LIVING WITH SERIOUS ILLNESS

**THIS GUIDE** IS FOR YOU AND YOUR LOVED ONES

## SECTION 2

Living with Serious Illness

A background image of purple flowers, likely columbines, with yellow centers, is visible on the left and right sides of the page. The main content is on a white rectangular background.

## SECTION 2: LIVING WITH SERIOUS ILLNESS

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**ALSO AVAILABLE:**

**SECTION 1: YOU ARE DIAGNOSED WITH A SERIOUS ILLNESS. NOW WHAT?**

**SECTION 3: CHANGING GOALS OF CARE**

For a **DIGITAL VERSION** of all 3 Sections, visit:

<https://cdphe.colorado.gov/palliative-care> or

<http://www.centerhealthcareanalytics.org>.

# INTRODUCTION

We are pleased to share with you the **Colorado Palliative Care Guide: Support for People Living with Serious Illness**. This Guide is here to help support you to manage this time better. It will help you understand palliative care and what it can offer.

This Guide is here for you: a person who has a serious illness or health condition. It is also here to help the people you love. We hope it gives you more support and less confusion during this time.

## **Serious illness often comes with:**

- Difficult symptoms
- Challenging treatments
- Complex input from a number of doctors
- Stress on you
- Stress on the people who help care for you
- Doctors who may not be coordinating your care
- Care in different settings and with different doctors
- Costly medicines and treatments
- Access to and cost of food
- More responsibilities for your loved ones

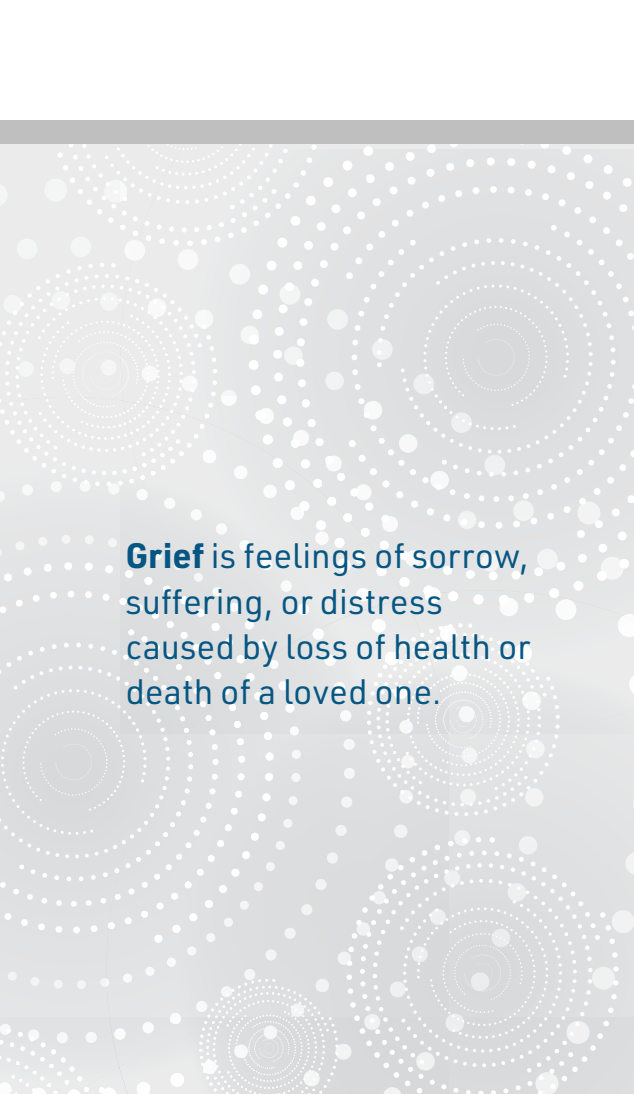
A team that helps support you through serious illness provides **palliative care**. It focuses on:

- Communication
- Your goals for your healthcare
- How you are able to enjoy your life

You can receive palliative care in addition to care intended to cure your illness.

**A serious illness** is one which negatively impacts your life over time and may even lead to end of life.





**Grief** is feelings of sorrow, suffering, or distress caused by loss of health or death of a loved one.

**A person facing serious illness may go through many forms of grief. It may affect how you manage or make choices.** Grief over a serious illness shows up in many ways. All these ways are real, and they are important to address. Grief can make people feel:

- Sad
- Confused
- Forgetful
- Angry
- Physical symptoms
- Losing the ability to communicate with your loved one

If a person ignores grief, it can make the experience of illness worse.

### **TO LEARN EVEN MORE:**

In this Guide, we share a lot about palliative care with you.

If you want to learn even more, you can go to the Colorado Department of Public Health and Environment Palliative Care webpage: <https://cdphe.colorado.gov/palliative-care>.

There, you can also find a complete list of palliative care resources and providers.

# PALLIATIVE CARE GUIDE

## QUESTIONS YOU MAY HAVE ALONG THE WAY

### When healthy: At any age

- Why do I need to think about this when I am healthy?
- What would I want if I become seriously ill or injured?
- What is the difference between a living will and an advance directive?

### Worried about symptoms

- When should I see a healthcare provider and what questions do I need to ask?
- Where can I get more information about my specific symptom and treatment options?
- What do I need to consider if I become seriously ill?

### Diagnosis

- What does my diagnosis mean and what can I expect?
- What decisions do I need to make?
- Where can I get more information and support?
- What do I tell other people? How should I tell them?

### Early in the journey

- What can I expect now?
- How do I set priorities?
- How will I manage my daily life, including employment, family, etc., now and in the future?

### Changes: When the illness or health condition worsens

- What will happen to me in the future?
- Who will provide the help I might need?
- Is my healthcare agent prepared to follow my wishes if I become unable to speak for myself?

### Recovery and survivorship

- How do I live with the threat of my illness or condition coming back and what will happen if it does return?
- How do I live with the after-effects of treatment and the trauma I've experienced?
- Will the old me ever be back?

### End of life, dying, and death

- How will I know I am nearing the end of my life?
- What are my ideas about a good death?
- How can I make sure my wishes about the end of my life are expressed and followed?

**Quality of life** means how you are able to enjoy life activities and to live based on your own values.

### **What is palliative care?**

**Palliative care** is specialized medical care for people with serious illness. No matter the diagnosis, this type of care provides patients with relief from symptoms, pain, and stress.

The goal of palliative care is to improve the **quality of life** for both you and those who matter to you. A team of doctors, nurses and other experts provide palliative care. These other experts work with a patient's doctor to give an extra layer of support.

Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment.

*Adapted from Colorado Standards for Hospitals and Health Facilities, Chapter 2 – General Licensure Standards (6 CCR 1011-1 Chap 02)*



## ■ MEETING YOUR PALLIATIVE CARE TEAM

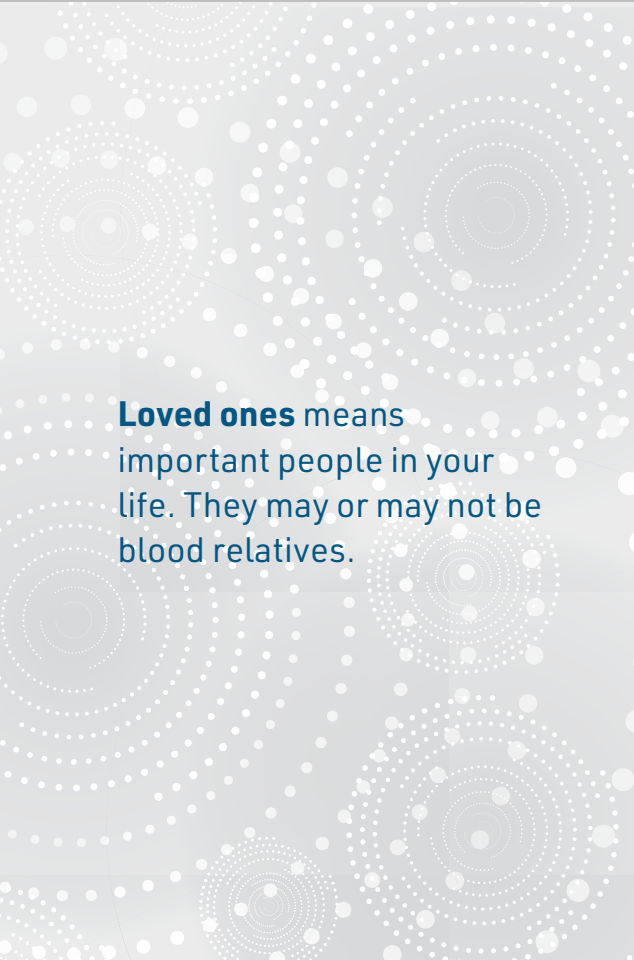
This is what you may do at your first visit with a palliative care team member or team:

- Define who you are as a person, your values and how these affect your healthcare choices.
- Discuss your diagnosis, treatment options, and what you hope treatment can achieve.
- Share about your symptoms.
- Learn how your palliative care team may help you and your family.

**If you have a health plan,** review your benefits. Be sure to review palliative care benefits. In our State, you may be able to change your health plan if you have a change in your health status. This is the case even if it is not open enrollment time.

**If you are a veteran,** check with Veteran Affairs to see if you can receive Palliative Care benefits.





**Loved ones** means important people in your life. They may or may not be blood relatives.



## What to expect when meeting with your palliative care team

How often you meet with members of your palliative care team will depend on you and your **loved ones** needs. It will also depend on your illness.

Here are some tips for when you do meet with them:

- Do not assume your palliative care team knows what you do or do not understand. You can help by offering your own sense of that. For instance, you can say:
  - "I understand the symptoms I am likely to face as this illness advances are..."
  - "I am not sure as to when I should call for help."
  - "I do not understand my treatment choices."
- Ask for clear guidance on when it would be urgent to call the doctor or the hospital based on your diagnosis. Make a plan so you know:
  - When should I call the clinic?
  - When should I see each specialist?
  - When should I seek emergency care?
- You have the right to understand what it means to have or not have a certain treatment. Be sure you understand:
  - The risks and benefits of treatment
  - The risks and benefits of no treatment



- You also have the right to explore alternative and complementary approaches. These may be:
  - Acupuncture
  - Reiki
  - Massage therapy
  - Herbal treatments
  - And more

Be sure to tell your doctors about any approaches you are getting or hope to get in case they interact with other treatments.

- Make sure you have filled out your advance care plan documents. Make sure you have shared and talked with all of your doctors about them.
- Before the appointment, write your questions down in a notebook.
- There may not be time to cover all of your questions in a single appointment. So, start your list with the questions that are most important to you.
  - Ask for a longer appointment if you have a lot of concerns or if you have to travel a long way. Your doctor may or may not be able to offer extra time.
  - If you can, take someone you trust with you. That person can help you ask your questions, understand the information, take notes, and talk with you afterwards.
- Try to schedule appointments during the best time of day for you. Schedule them at times when your symptoms are mildest.
- Remember this is your care. Your concerns and values should guide the decisions you make.





## ■ IF YOU ARE A CAREGIVER, HOW YOU CAN OFFER SUPPORT

If you help care for a person with a serious illness or health condition, there are many ways to offer support.

### **You can:**

- Ask what they want and need. Be aware that the person's needs and desires may change. Offer specific helpful actions.
- Learn what the impact will be on the person if the condition changes. Plan for help with things like meals, errands, household duties, rides to appointments, and more.
- Offer to go along to a healthcare appointment and take notes.
- Discuss who to tell about the diagnosis and how to tell them. Also discuss who not to tell yet. Sometimes privacy is more important than sharing.
- Sometimes the person has symptoms but may be worried about what the diagnosis could be. In this case, you can gently offer a healthcare appointment.
- Ask open ended questions to start conversations. For instance, "How are you feeling about the diagnosis?" Offer empathy and listen. Sometimes it is best not to offer advice.
- Be aware that you, and the person you are caring for, are grieving losses along the way. You are also anticipating losses in the future. When you are grieving, you may feel many emotions. Some of them may be surprising and unexpected. It is also common to feel overwhelmed, tired, and forgetful. Be aware of your experience and talk to your loved ones and doctors about your feelings.



## ■ MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST) FORM

There is a form called Medical Orders for Scope of Treatment (MOST). Your doctor might discuss this form with you. Or you can ask them whether you should have one.

Here are some questions and answers about the MOST form:

### **Who is the Colorado MOST form for?**

It is for people who:

- Have a serious illness or condition
- Are frail or in poor health
- Are nearing the end of their life, no matter their age

### **What type of form is it and how does it get filled out?**

The MOST form is a medical order that your doctor signs. It states what your wishes would be if there were a medical emergency.

You complete the form with your doctor. Then they sign it. In Colorado, you keep the original, signed MOST form. It is recommended you post your MOST form at home in a visible place like the fridge. Your doctors should keep copies of the MOST form in the medical record.

### **What is on the MOST form?**

The form consists of 3 parts:

- Whether you would want attempts at resuscitation, like CPR
- The level of care you want to receive
- Whether you would want artificial nutrition, like a feeding tube

### **Is having a MOST form my choice?**

Yes. Having a MOST form or not is your choice. You should never feel that you must complete one. You and your doctor can decide together whether it is time to use the MOST to reflect your wishes as clear and specific medical orders.





### **Can I change my choices on the MOST form?**

Yes. You have the right to change the choices on your MOST form at any time.

A doctor should review the form with you every so often. This is to know if they are still your choices. If you have changed any of your choices, they can make changes. Or they may complete a new MOST form.

When they review this with you, they will then mark a new date and sign on the backside of the form. Or they may complete a new MOST form and sign that.

If you want to make changes before a doctor reviews it with you, ask for an appointment to make changes to your MOST form. Or you can ask to make changes at your next healthcare visit.

### **Is the MOST form the same thing as an Advance Directive?**

No. They are not the same. The MOST form is a medical order that you and your doctor sign. The Advance Directive is a legal form that you sign.

The MOST is a form that supplements an Advance Directive.



## The Difference between the Advance Directive and MOST

The Advance Directive and the MOST are really different. Still, it's easy to confuse the two. This chart shows you the differences.

	<b>ADVANCE DIRECTIVE</b>	<b>MOST (Medical Orders for Scope of Treatment)</b>
<b>Who is it for?</b>	Everyone 18 and older.	People with a serious illness or who are very old and frail.
<b>What kind of document is it?</b>	It is a legal document.	It is a medical order.
<b>Who signs it?</b>	You fill it out and sign it. Also, your health care representative signs it and witnesses or a Notary.	Your doctor fills it out with your input. Then signs it.
<b>Do I need a lawyer?</b>	No.	No.
<b>Who keeps the form?</b>	You keep the original where loved ones can find it. You give a copy to your health care representative and your doctor.	In Colorado, you keep the original, signed MOST form. It is recommended you post your MOST form at home in a visible place like the fridge. Your doctors should keep copies of the MOST form in the medical record.
<b>Can I change the form if I change my mind?</b>	Yes. You can tear up the old one. Then write a new one where loved ones can find it. You give a copy to your health care representative and your doctor.	Yes. You can ask for an appointment with your doctor to change it.
<b>What if there is a medical emergency and I cannot speak for myself?</b>	Your health care representative speaks for you and honors your wishes.	The ambulance staff, hospital staff, and doctors will look for the MOST form and follow it.



## ■ THERAPIES TO MANAGE PAIN AND SYMPTOMS

Medications for pain and to manage symptoms can be helpful. And there are also therapies that can support you while facing serious illness. Your doctor may call them “integrative or alternative therapies”.

Here are some that you can do on your own that can help manage pain or symptoms:

- Gentle exercise and time in nature can relax the mind and emotions. They may provide stress relief and lower the pain. These include walking, tai chi, and yoga.
- Meditation is a mind-body practice in which you focus on something. This could be an object, word, or breathing. It helps you to lower stressful thoughts or feelings.
- Relaxation therapy may involve tensing and relaxing muscles all over the body. You can use it with music, positive statements and imagining peaceful images. It may help reduce muscle tension and stress, lower blood pressure, and control pain.

Here are some other therapies you can do with experts that can help manage pain and symptoms:

- Acupuncture involves inserting tiny needles into the skin to stimulate specific parts of your body. It may help manage pain and other symptoms.
- Massage therapy is a treatment where the expert rubs, taps, and strokes the soft tissues of the body. It may help you relax as well as relieve stress and pain.
- Reiki and healing touch are gentle, hands-on therapies that use light touch to promote relaxation and peace. It may improve sleep and provide a feeling of well-being.
- Counseling can provide emotional support for you and your loved ones.
- Yoga is a series of poses, movements, and breathing exercises. It often includes meditation. Yoga may help manage stress, improve movement and help with fatigue.

Grief is part of having a serious illness. Grief can show up in physical ways, such as:

- Stomach aches
- Headaches
- Tension
- Trouble breathing
- Sleeping well

These therapies can help to relieve those, even if they do not appear to be grief responses.

**Discuss any of these types of therapies with your care team before starting.** They can often be helpful. But they can also interact with other medical treatments. Or, in some situations, they can pose added risk.

**To find palliative care providers, go to: <https://cdphe.colorado.gov/palliative-care>.**

Please check with your insurance provider regarding payment for palliative care. If you are a veteran, also check with Veteran's Affairs.

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