



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

THIS GUIDE IS FOR YOU AND YOUR LOVED ONES

SECTION 3

Changing Goals of Care

A background image of a field of sunflowers under a bright sky. The sunflowers are in various stages of bloom, with some fully open and others as buds. The lighting is warm, suggesting late afternoon or early morning.

SECTION 3: CHANGING GOALS OF CARE

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ALSO AVAILABLE:

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

SECTION 2: LIVING WITH SERIOUS ILLNESS

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

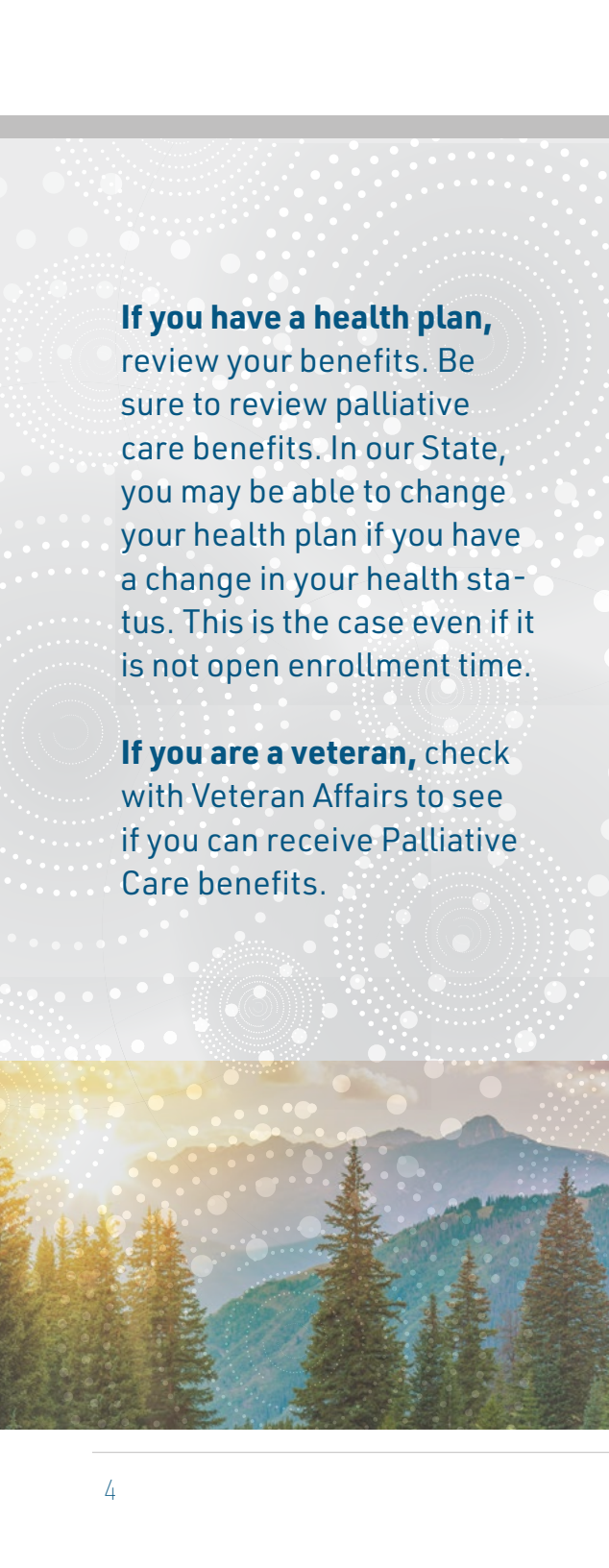
A team that helps support you through serious illness provides **palliative care**. It focuses on:

- 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.



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.

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)

■ WHAT IF YOU RECOVER FROM SERIOUS ILLNESS?

Some people will recover from serious illness. Others may have a condition that becomes stable over time. Here, we offer support for people that have survived or are living with a long-term illness.

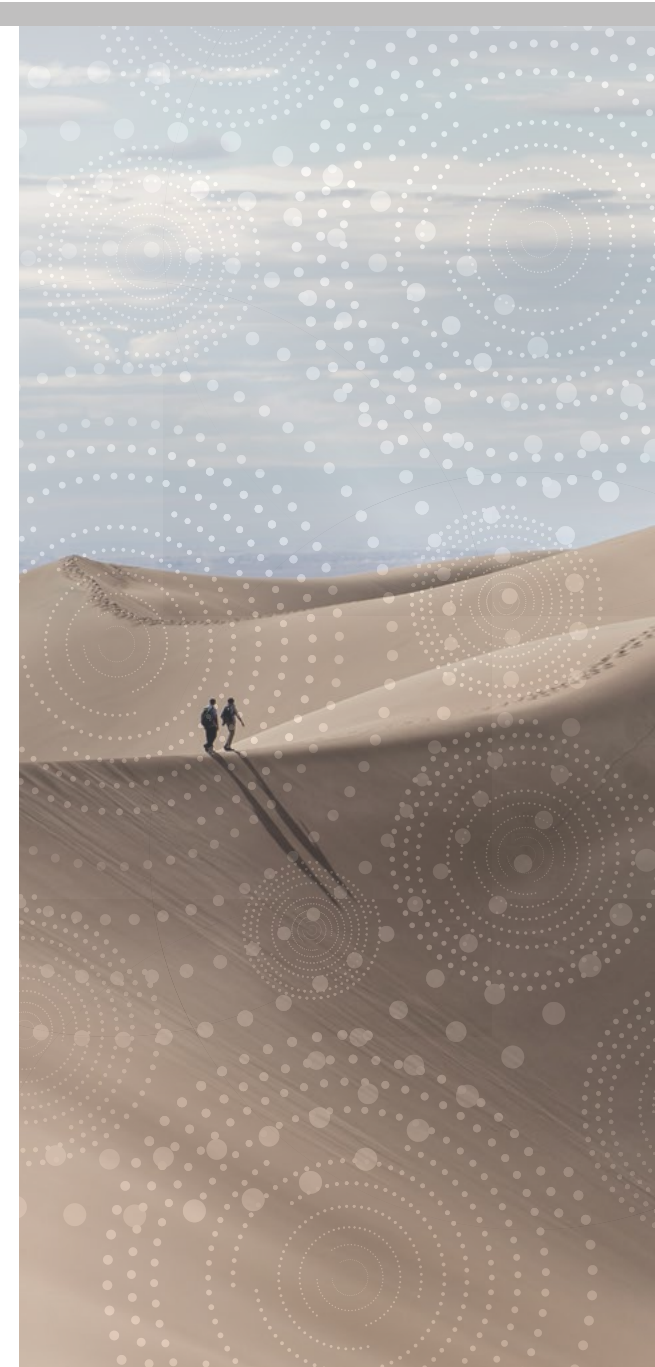
Common concerns to discuss with your palliative care team or doctor


These are questions you may want to ask your palliative care team members or doctors. You may have other questions. You can write them down and talk about them together.

- How do I move forward and adjust to living with serious illness?
- 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 have lived through?
- Will the “old me” ever be back?

What to expect if you recover from or survive serious illness:

- You may feel a sense of loss as you adjust to a life that no longer revolves only around being ill.
- Your doctor may or may not understand the long-term effects of your treatments.
- It is normal to feel cautious about accepting that you are in remission or recovery. Loved ones may watch you very closely for the possible return of symptoms.
- Know that people may still worry about your health. Give your loved ones time to adjust to the new reality. Those who see you less often may still be thinking of you as very ill.
- You may wonder why you continue to survive. You may feel guilt. This may be the case if you knew others with a similar illness or condition who died.
- Palliative care may keep being useful. This may be the case if you are dealing with symptoms from the after effects of treatment.





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

What you can do to help yourself:

- Make plans that give structure to each day.
- Talk with your loved ones about how you are feeling and the changes you are going through.
- Counseling or support groups may be helpful.
- Reflect on the lessons from your experience. You may find that you can now grieve the changes you went through more so than when you were in the middle of them. Grief is a normal part of thinking about what you went through.
- Talk with your doctors about what to expect and possible treatments going forward.
- Volunteer or find ways to help others. This may help you get back to feeling whole again.

Support for loved ones who help care for a person with serious illness

If you are helping to care for a person with serious illness, here are some things you can do to support them and yourself.

- Know that your relationship may change as the illness or a health condition is less dominant.
- As your relationship changes, listen for ways to most help your loved one. Also, share your feelings and concerns with your loved ones.
- Listen to your own needs. Take time to care for yourself.



Goals of care means the medical care you want based on your values and what is most important for you.

■ WHAT IF YOUR ILLNESS ADVANCES?

Sometimes your illness or health condition may worsen. If that occurs, talk with your loved ones and palliative care team about what your **goals of care** are now.

Common concerns to discuss with your palliative care team or doctor

These are questions you may want to ask your team members or doctors. You may have other questions. You can write them down and talk about them together.

- 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?
- What do I do if treatments are no longer working?

What to expect if your illness worsens

- More symptoms may occur. They may come more often or they may be more intense. New symptoms or complications may arise without warning.
- You may fear:
 - Not being able to do the things you enjoy
 - Not being able to do things on your own
 - The impact on work
 - Physical changes
 - Many other things
- You may find it harder to keep doing all the things you normally do. Fatigue is a large part of many illnesses and can be frustrating. This is sometimes called adjusting to a “new normal.”
- If you are suffering, you may think you must stick it out. Or you may think asking for help is a sign of weakness. It takes courage to ask for help.
- You may want to think again about what treatment options you want.
- You may be filled with a deeper appreciation for those you love and for life itself.
- You may grieve the life you had, before your illness. Or you may start to feel grief as you think about what is to come.





What you can do to help yourself

- Discuss with your doctors what to expect as your disease or condition advances. You have the right to know the risks and benefits of treatments. You have the right to say no to treatments you do not want.
- You may find it hard to know when to accept medications for pain and when to try other options for relief. A palliative care team can offer guidance about pain and control of other symptoms.
- If you have not yet engaged with palliative care, it is not too late. You can receive palliative care while getting curative treatments. Ask your doctor to make a referral.
- Make sure all your doctors know of and will honor your wishes, including doctors who may care for you in your home. Make sure they have up to date advance care documents on record.
- Make sure you have taken all the legal steps to:
 - Have your wishes honored
 - Protect what you have
 - Look after any dependents
- Consider working with an occupational therapist. They can recommend medical equipment or supplies that may help you live at home in more comfort.

How you can support your loved ones

- Help sort out what is the right amount of help for you. This will depend on how much privacy or independence you want. Let family members know in a loving way when they can help you more or help you less.
- Tell loved ones how you are doing and what you need.
- Know that those around you may be grieving. If you are willing, talk with them about their feelings. If you are not, invite them to find support for themselves.

Hospice

If you no longer wish to receive curative treatments, talk with your loved ones and palliative care team about whether hospice is an option.

What is Hospice?

Hospice provides comprehensive care to the patient as well as support for the family. But in hospice the focus is on comfort rather than curative treatment.

A person can get hospice if they have a terminal illness and their doctor believes they have 6 months or less to live if the illness runs its natural course.

Hospice is often offered in the home. It is also offered in nursing homes, adult family homes, assisted living and other supportive residences. There are also hospice units in some Colorado communities.

You can ask for a hospice care evaluation if you are concerned about your prognosis. Learn how they can help you.

Learn more about **hospice**.
People often say they wish they
had asked for hospice sooner.



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

The person that cares for you is called a **caregiver**.

Respite is a short break for caregivers. Respite gives a caregiver the chance to step away. They can take this break knowing that their loved one is well cared for by bringing in professional care.

■ ROLES AND NEEDS FOR LOVED ONES

This is how you can help support a person living with a serious illness or health condition

- Invite them to talk about their hopes and fears. Allow for moments of silence.
- Help record questions to ask the doctor and take notes.
- Offer empathy and listen. Sometimes it is best to withhold advice.
- Offer hands on support such as rides to appointments.
- Ask what they want and need. Be aware that the person's needs and desires may change. Respond as you can to those needs.
- Ask open ended questions like, "What do you hope for in this moment?". Listen to what they say.

How to support yourself as a caregiver:

- Think about how you will know when you need a break or need more help.
- Consider getting **respite care**. Respite care is when someone steps in to help your loved one and you get a break. This gives you a break so you can attend to other needs.
- Work to find balance in your life. Try not to give their illness your total focus. Pay attention to cues that they may want to focus on other things.
- Talk with your loved one about how much to tell others about their illness.
- If you have an idea about how to help, offer your idea and ask if it might be helpful. Give them room to decline.
- Learn how their illness may change. Think about making a plan for more services if needs increase. Also, know that the relationship with them may change, too.
- It is normal to start to grieve the loss of a loved one before they are no longer here. Ask your team Social Worker or Chaplain for grief resources and support.



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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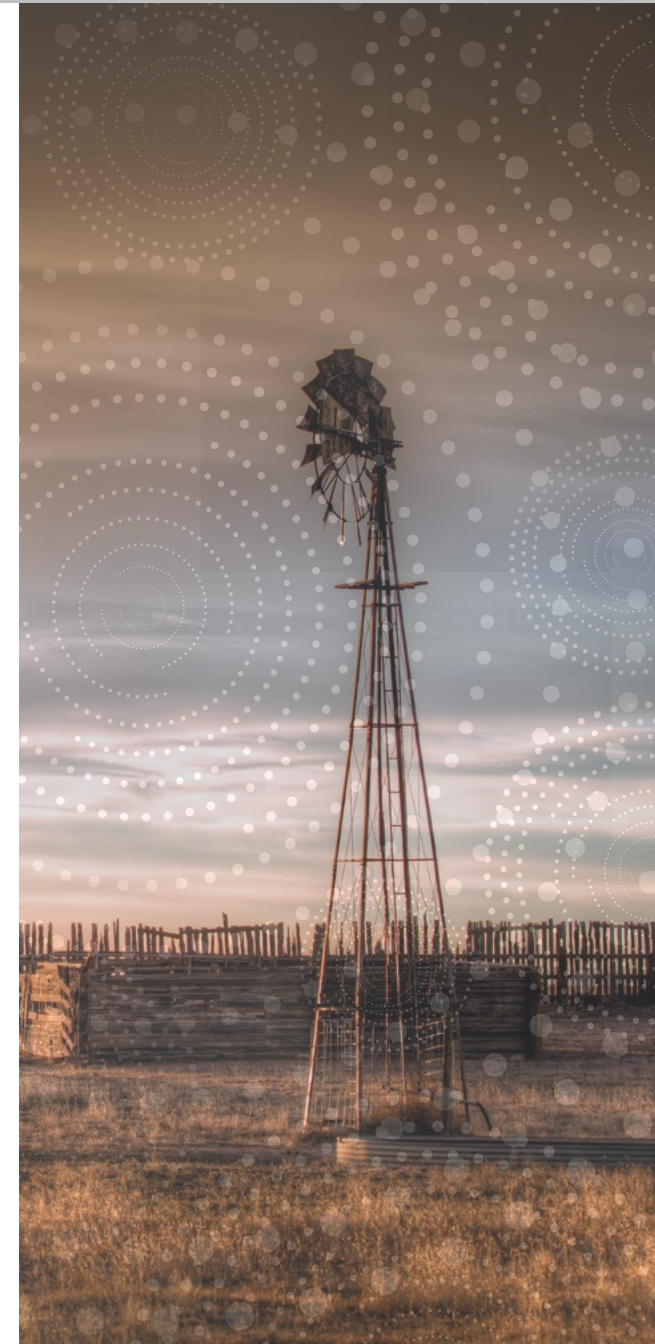
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