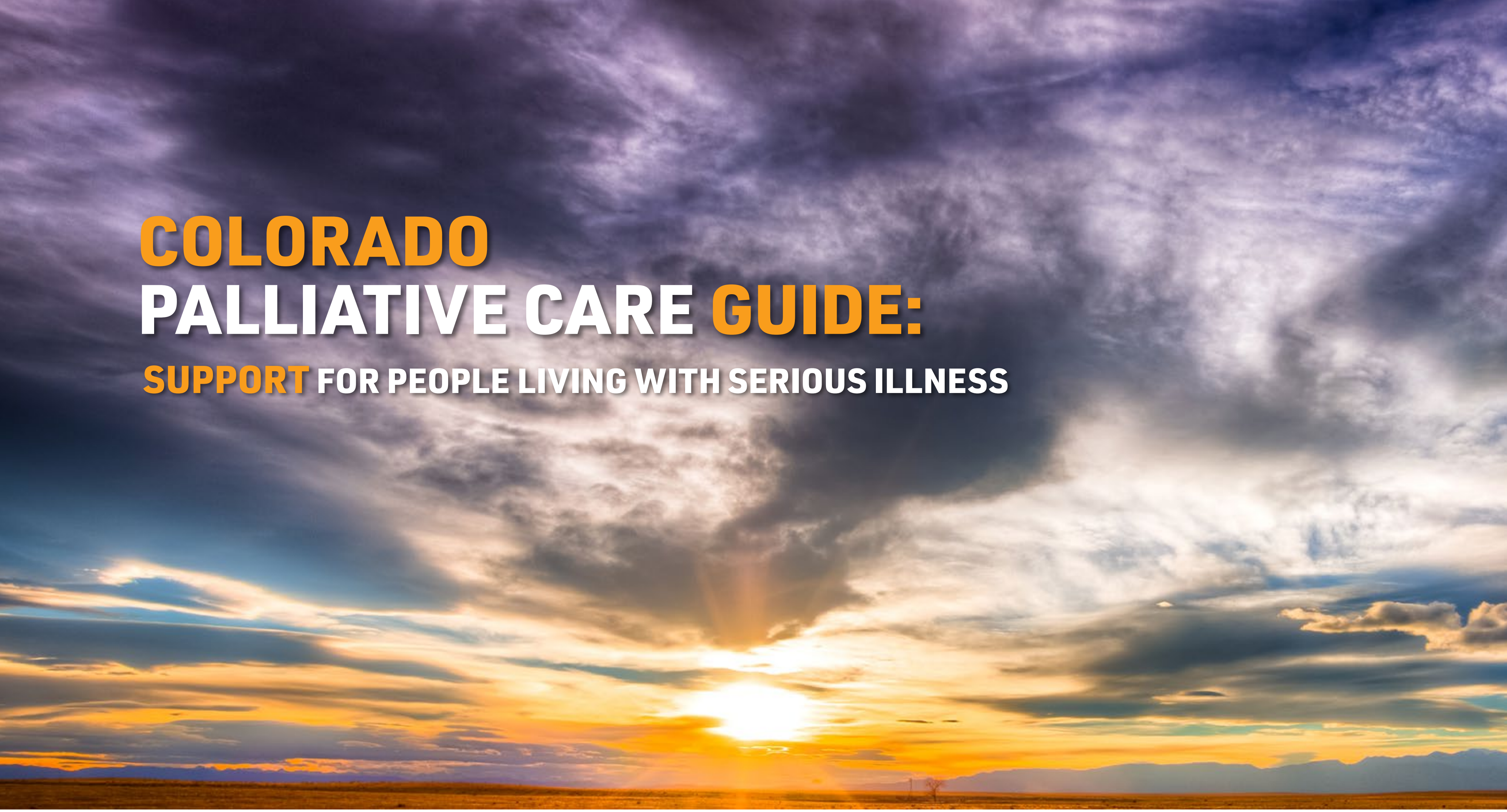
# COLORADO PALLIATIVE CARE GUIDE:

## SUPPORT FOR PEOPLE LIVING WITH SERIOUS ILLNESS

THIS GUIDE IS FOR YOU AND YOUR LOVED ONES



# COLORADO
# PALLIATIVE CARE GUIDE:

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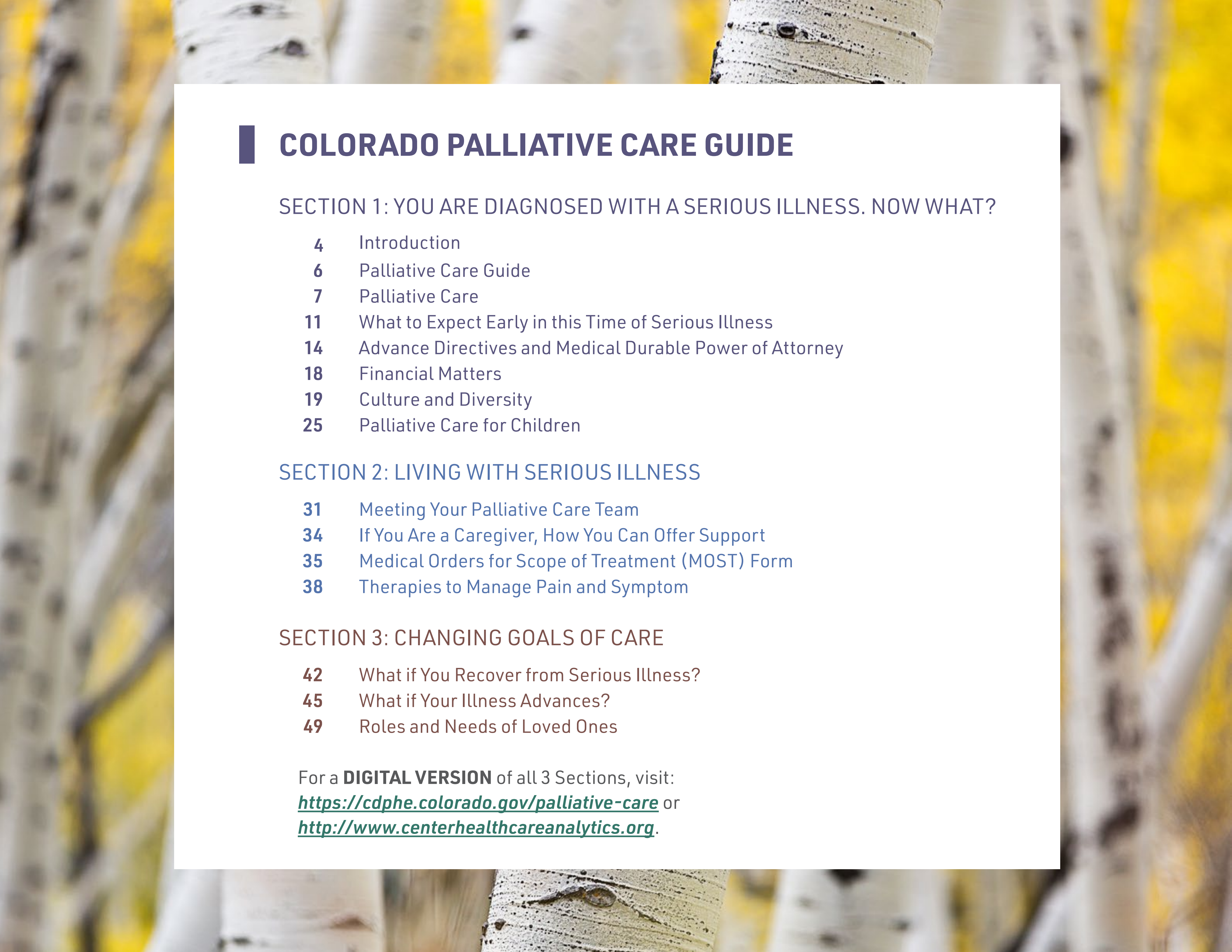
## SECTION 1

### You Are Diagnosed with a Serious Illness. Now What?



# COLORADO PALLIATIVE CARE GUIDE

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

## SECTION 2: LIVING WITH SERIOUS ILLNESS

## 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.

**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:

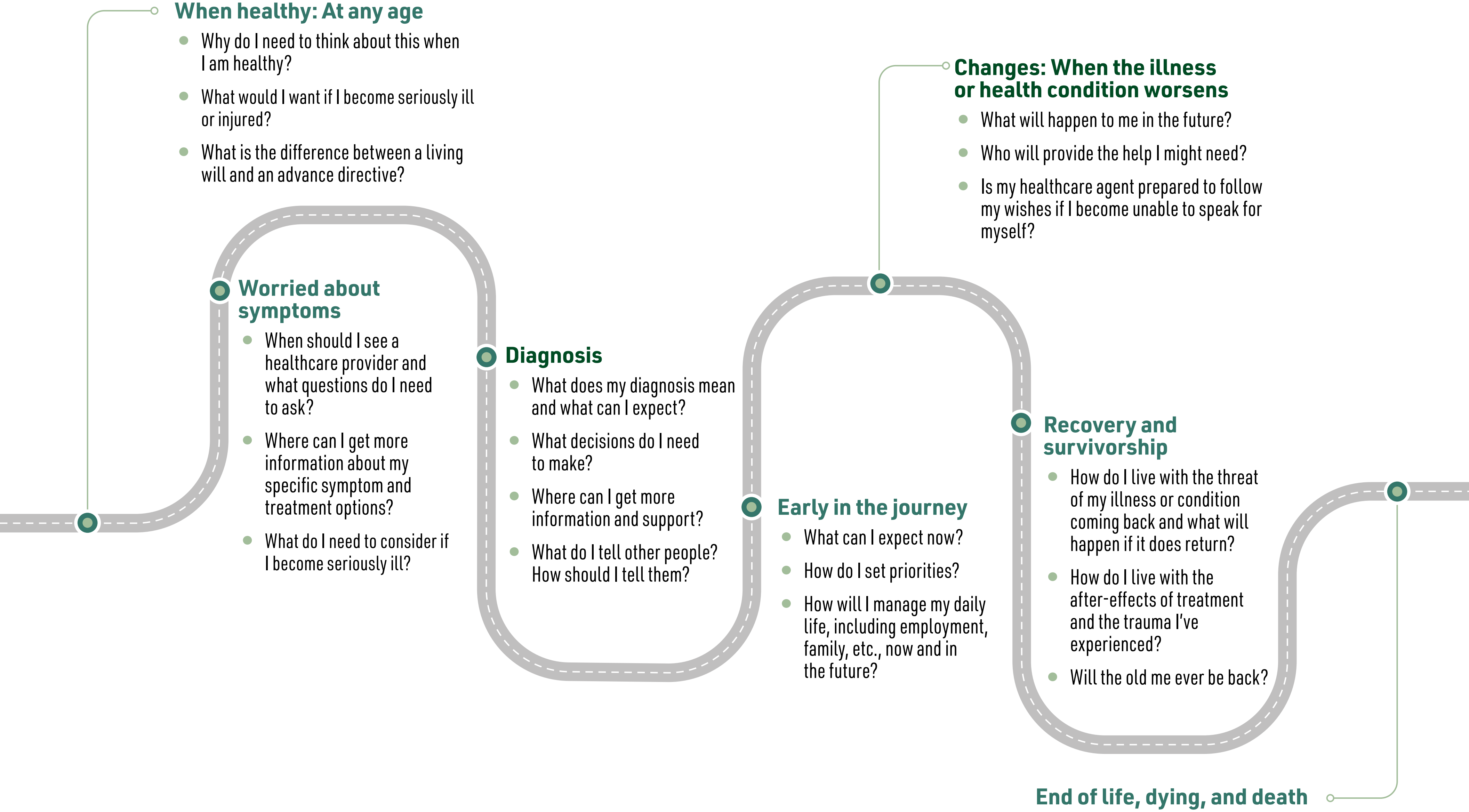
In this Guide, we share a lot about palliative care with you.

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.

# PALLIATIVE CARE

## 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)*

## Who is palliative care for?

**Palliative care** is for everyone. It is for people of all races, ethnicities, religions, or financial status. It is about keeping you at the center of care. It is about making sure the plan of care and the way care is given is tailored to meet your needs.

## When should you begin palliative care services?

It is helpful to begin soon after you have been told that you have a serious illness. Ask your doctor about palliative care and how it can help you and your family.

## What if you do not want to start palliative care services soon after you learn you have a serious illness?

You have the right to choose when and if you start palliative care. You can ask for it at any point during a serious illness.

## Where can you receive palliative care services?

They can begin with your primary care doctor or specialist. These can take place in your home, the hospital, or a clinic**.** The palliative team works with your current doctor, they do not replace them.

## What if you live in a rural area without these services?

Rural areas are working to offer more access to programs and services. This includes using **telehealth**. Ask your doctor about this.

**Telehealth** is sometimes called telemedicine. It means connecting with a doctor through an audio only or a video and audio call. Using telehealth, a doctor can:

- Assess you
- Give you a treatment plan that fits your needs
- Recommend testing
- Prescribe medication

**Social Workers** address a person's physical, mental, and social, and spiritual well-being. They address these in all stages of a disease.

**Chaplains** work with you and those who matter to you to provide these supports and counseling:

- Spiritual
- Pastoral
- Emotional
- Grief

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

## Who is on a palliative care team?

A team may include:

- Doctor: by doctor we mean physicians, nurse practitioners, and physician assistants.
- Registered nurses
- Social workers
- Chaplains

The team members work together so that each member of the team:

- Understands your **goals of care**
- Is aware of how the team will contribute to help meet those goals

Palliative care team members might be part of:

- Clinics
- Cancer clinics
- Hospitals
- Palliative Care and Hospice organizations
- Other organizations in the community, such as rural health organizations

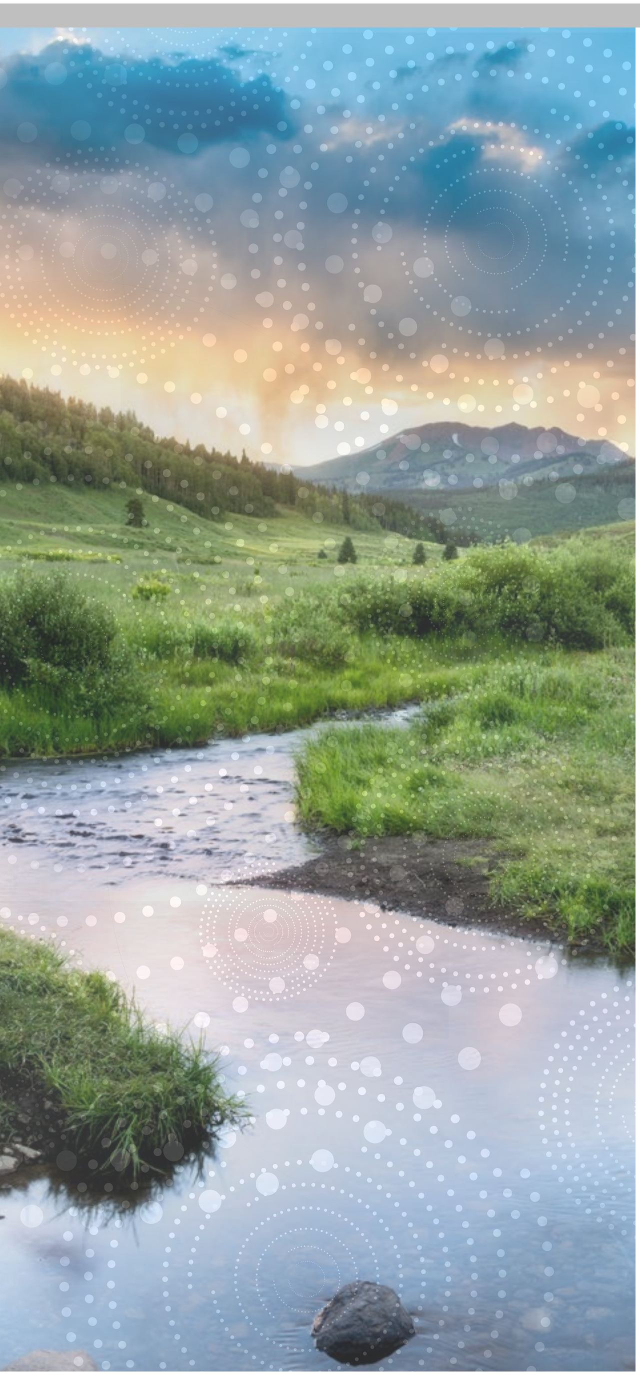
## Common concerns to discuss with your palliative care team early in this time of serious illness

You might want to ask your team members some or all of these questions.

- What does my diagnosis mean and what can I expect? How much of this can I control?
- What decisions do I need to make? And are these decisions final?
- How do I identify what is most important to me?
- What do I tell other people? How should I tell them?
- How will I manage my daily life now and in the future? This includes my job, family and more.

**Here are some questions a palliative care team member might ask you.**

- What do you understand about your illness?
- What is most important for you now?
- Going forward from here, what are you hoping for?



## WHAT TO EXPECT WHEN YOU HAVE A SERIOUS ILLNESS

Every person is unique and responds in their own way.

- You may be worried about what this illness could mean for your future.
- You may not fully understand what your condition means. You may feel embarrassed about things that are confusing. You may not feel comfortable to ask questions.
- It is likely you will feel many different emotions.
- Symptoms from the illness or treatments may start to impact your daily life. They may come and go without warning.
- You may have to decide about what treatment to choose. Each treatment has its own risks and benefits. You may find this hard.
- You may have spiritual questions. You may feel punished or abandoned and say, "why me?"
- You may feel overwhelmed or are grieving. So, it may feel hard to keep doctors and information clear in your mind.
- Your family and friends may not know what to say. Each will have their own response. Some may want to protect you, and others may withdraw.

## What you can do for you

These are some things you can do to support yourself in this time.

**Do this first!** The first and most important thing you can do is appoint the person who you want to be your healthcare decision maker when you can no longer make your decisions known. You do this through a **Medical Durable Power of Attorney (MDPOA)** form. See page ***https://cdphe.colorado.gov/advance-care-planning*** for information about this.

- Think about what **quality of life** means to you. Your ideas are likely to change as your condition changes.
- Keep a notebook. So, when you meet with doctors you can take notes to review later. You can review them on your own, or with family and friends.
- Think about bringing a family member, or friend, to appointments to help support you.
- If you do not understand something a doctor says, ask them to explain it in a different way.
- Accept help that others offer. Be honest about what is most helpful.
- Some illnesses change your ability to have conversations, such as dementia and Parkinson's. So, express your needs while you can. Talk about them more than once so people who matter to you can understand your needs well.
- Think about finding an online group or counseling for just you or your family. This can help you deal with the stress of living with illness. It can also help you be clear about what matters most to you.
- Know that your family members will have their own fears and sorrow. They may need support from others that you cannot provide.

In a MDPOA, you appoint your **Healthcare Decision Maker or Agent**. This should be someone only you trust to speak for you in the event you are unable to speak for yourself due to illness

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

## What you can do for your loved ones

These are some things you can do to help your loved ones during this time.

- Fill out a Medical Durable Power of Attorney (MDPOA). It a gift you can give your loved ones to make this time easier for them. They will know your wishes and who will speak for you if needed.
- Share your values and what matters most to you with your family and doctors involved in your care decisions. See the Advance Directives section below.
- Let your loved ones know what you need. Do not expect others to read your mind.
- Get information about services to support your family from your doctor.
- People grieve differently. Let and help others to grieve as they need to, without expectations that it should be a certain way.
- Show interest in other people and topics outside illness. It is healthier for you and makes life less stressful for others.
- Create a notebook to help your family find your important documents, cards, numbers, and Personal Identification Numbers (PINs). These might include your:
    - Social security number
    - Health plan
    - Driver's license
    - Computer passwords
- Organize your legal and financial paperwork. Be sure to be clear about finances with those who need to know.
- If you have young children at home, seek support for them. Learn how to discuss the situation with them honestly, and at a level that fits their age.

# ADVANCE DIRECTIVES AND MEDICAL DURABLE POWER OF ATTORNEY

In this Guide we share how important it is to appoint a healthcare decision maker. We share about this in the Medical Durable Power of Attorney (MDPOA) part below. We also share about this in the Medical Orders for Scope of Treatment (MOST) form in **Section 2**. You can find the Colorado MDPOA form here: ***https://cdphe.colorado.gov/advance-care-planning***.

We do not share about other advance care planning documents in this Guide. These include the Living Will and Colorado CPR Directive. If you want to learn more about those, you can go to ***https://cdphe.colorado.gov/advance-care-planning***.

Making healthcare decisions for yourself or for someone who is not able to do so can be overwhelming. That is why it is important to get a clear idea about what you prefer. Make a plan while you can make decisions and can take part in legal and financial planning together.

## Assign a healthcare decision maker in the MDPOA

What happens if or when you are not able to make your own medical and financial decisions? Who would you trust to make them?

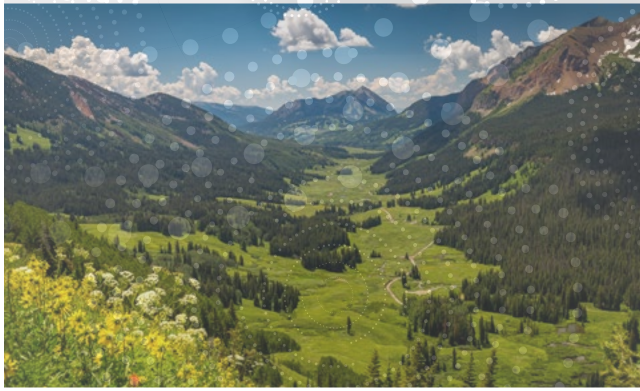
It is important to think about and then know what your wishes are. This is so your loved ones and doctors can honor them.

Here is the best way to make sure your wishes are followed:

- Think about what is important to you.
- Share what is important to you with those who may need to speak for you.
- Write your wishes down in any of the advance planning documents. Share them with those who may speak for you and your doctor.
- Appoint a trusted person to be your healthcare agent in a Medical Durable Power of Attorney (MDPOA) form. Review your wishes with them.
- Confirm that the person you have chosen is willing to carry out your wishes if you are not able to speak for yourself.

An **Advance Directive** is a legal document. In it, a person states their wishes about what medical care they would want if they were not able to make medical decisions because of an illness or injury. This may include:

- A MDPOA
- A Living Will
- A Colorado CPR Directive
- A MOST
- 5 wishes
- And other forms



**Use this checklist** to make sure you have healthcare and financial matters in place. Do it now before serious illness advances or a healthcare crisis. Find a family member, close friend, or organization that can help you fill out these forms.

- **Start talking early with your loved ones** while they can hear and talk about your decisions. Your wishes may change as your illness advances. But it is important to start early.
- **Fill out forms that state your healthcare and end of life wishes**. Then share them with your loved ones. Get legal advice if you need it.
- **Review plans often.** Update forms every year or as conditions change. This could mean health changes, divorce, a move, or when your MDPOA is no longer able to speak for you.
- **Put important papers on the fridge**, such as the MDPOA and MOST form. This is because that is where first responders look for them. Make sure a trusted family member or friend has copies and knows where to find any other instructions.
- **Make copies of healthcare directives**. Give copies to each doctor you see so they can add them to your medical files. Have them entered into your hospital's medical record, if you have a hospital you go to.
- **Let your doctor know** you have assigned a MDPOA or decision maker.
- **Reduce anxiety by planning ahead** for funeral and burial plans.

## 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.

| | ADVANCE DIRECTIVE | MOST (Medical Orders for Scope of Treatment) |
|---|---|---|
| **Who is it for?** | Everyone 18 and older. | People with a serious illness or who are very old and frail. |
| **What kind of document is it?** | It is a legal document. | It is a medical order. |
| **Who signs it?** | 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. |
| **Do I need a lawyer?** | No. | No. |
| **Who keeps the form?** | 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. |
| **Can I change the form if I change my mind**? | 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. |
| **What if there is a medical emergency and I cannot speak for myself?** | 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. |

A **Proxy Medical Decision-Maker** is chosen for you if you have not appointed one in a MDPOA. The decision-maker could be one of these:

- Spouse or Registered Domestic Partner (even if separated)
- Adult Children
- Parents
- Adult Siblings
- Adult Grandchildren
- Close Friends (who meet certain criteria)

## What happens if you do not choose a Medical Durable Power of Attorney (MDPOA)?

### Proxy Medical Decision-Maker

Ideally, you choose a MDPOA to make decisions for you before you can no longer speak for yourself, then that person makes medical decisions for you.

However, if you do not choose a MDPOA, then Colorado's proxy medical decision-maker law sets out the method to select who will make decisions about your healthcare.

Here is how the process would work:

1. First, your doctor must find that you are not able to make decisions for yourself. This must be recorded in your medical record.
2. Then your doctor, or someone acting under their direction, must contact all interested persons. "Interested persons" means your spouse or domestic partner, parent, grandparent, adult child, grandchild, sibling, and any close friend. The doctor may rely on those identified at first to notify other interested persons.
3. The interested persons are asked to gather to decide who should serve as your proxy and make medical decisions on your behalf. They choose the person who is close to you and is most likely to be informed on your current wishes. Hopefully, they can agree as to who that person should be.
4. Then that person is assigned to make medical decisions for you.

This process can take time and your care could be delayed. The care you want may not be the care you receive if you have not spoken with your loved ones about what you would want. If an interested person does not agree, they may petition the court to have a guardian appointed. They can do this if they do not agree with who was chosen as your proxy, or with the decisions your proxy is making.

If you regain the ability to make decisions for yourself, the proxy's authority is canceled.

## FINANCIAL MATTERS

Think about who you would want to make financial decisions for you if you were not able to. You might want to choose a trusted relative or friend.

You can assign someone to do that for you by filling out a special form. It is called a **Durable Power of Attorney for Finances (DPOA-Finances)**. This person may or may not be the same person that you choose as your Medical Durable Power of Attorney (MDPOA).

Each of these roles require different skills. So, choose the right person to make financial decisions for you based on their skills

**Durable Power of Attorney for Finances** is a document where you name someone to make your financial decisions if you become unable to do so.

**Cultural minority group** refers to racial, ethnic, or physical characteristics that may single out a person for unequal treatment.

## CULTURE AND INCLUSION

Living with a serious illness or a long-term condition is deeply personal. Your values and experiences come to the surface when you seek healthcare. These may be shaped by your:

- Family values
- Cultural or ethnic identity
- Religious or spiritual beliefs
- Previous healthcare experiences
- Gender
- Sexual orientation
- Support system
- And many other factors

All of these may influence how you, your loved ones, and your community grieve, as well as how you may find support.

If you are part of a faith-based, LGBTQ+, or cultural minority group, it can be a challenge to find doctors who understand your values and preferences. Sometimes your beliefs and expectations about care may conflict with those of your doctor. Some common concerns that may result in people not using palliative care are:

- Mistrust of the healthcare system and doctors
- Getting poorer care
- Discrimination or doctor bias
- Safety and disclosing personal information
- Whether your beliefs and values will be respected and heard

If your doctor does not discuss your beliefs, concerns, or needs with you, you may have to start the talk with them. You have the right to choose a doctor that you trust and addresses your concerns.

## To be sure that your needs are addressed, think about these questions:

- Who is important to include in making decisions?
    - Do you come from a culture where each person makes their own choices? Or does your culture consist of listening to many members of your family or group? Or does an elder of the family guide most decisions?
    - Is there someone you would like to bring with you to help you talk with your doctor?
    - Make sure your doctor knows how you would like decisions made.
- How much information do you want your doctor to give you about your diagnosis and care?
    - In some cultures, the family filters the medical details that the patient receives.
    - Do you prefer a family member to receive the information instead of you?
    - If so, be clear with your provider. Let them know who should be given the information.
- Do you trust your doctor to make good decisions with you?
- Some questions you can ask to make sure you find a doctor that respects you as a person are:
    - How would you and your team understand and respect my beliefs and values as a patient?
    - Tell me about when your team took care of a Latino, LBGTQ+, etc., patient. What did they learn? How did you support that person and their loved ones?
- Are there some things you want your doctor to know about you that might be helpful in planning your care? This might have to do with your family, faith, community, or beliefs.
- Are there any cultural taboos you may have about talking about illness or death? Your doctors need to understand those in order to care for you.

The term **Latino** refers to people with cultural ties to Latin America.

- Sometimes people are not comfortable talking about serious illness care with someone from a different race or background. Do you have any feelings about that which would be helpful for your doctor to know?
- Is your native language different from your doctor's? If so, you have the right to request an interpreter so that you can better understand your diagnosis and treatment options.

  Family interpreters may seem like they would be perfect for this task because they can also be a comfort. But, having a friend or family member as an interpreter is often not the best thing to do. This is because:

    - They a have personal attachment to you. They may not want to confuse or upset you or be the bearers of bad news. So they may withhold crucial information.
    - They may not understand all the legal, medical, or technical terms they are trying to interpret. They may leave words out. This can result in interpretation that is not correct.

So, ask for an interpreter. It is your right. And ask your loved ones to be there to support you and help you make decisions.

## Common Concerns

Palliative care focuses on you as a whole person. It helps to improve your physical, emotional, social, and spiritual well-being. Palliative care consults often include not only you but also loved ones. Here are some common concerns people have when they think about palliative care:

### What does palliative care even mean?

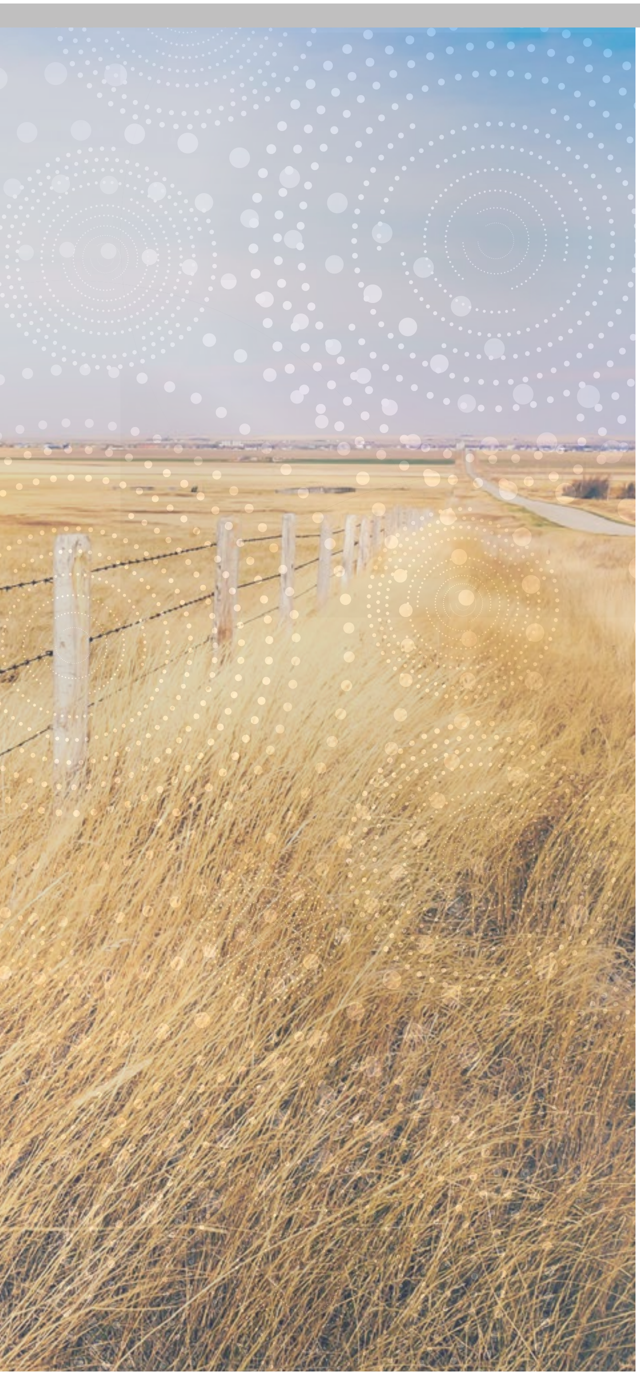
Palliative care is a team effort. It is focused on improving your quality of life by:

- Helping to manage your symptoms
- Talking about what medical care you want based on your values and what matters to you most
- Helping to address the fears or anxieties that are a part of living with serious illness

### If I fill out an advance care planning form, like an Advance Directive, it feels scary. It might cause me to get worse.

Advance care planning helps others understand your wishes if your illness gets worse. Ask yourself, would you want your loved ones to have to make difficult decisions without knowing what you would want?

It can really help your loved ones if you think about the kind of care you might want if your illness gets worse. If you are sick and cannot make your own decisions, your family will know what you want. This will ease their burden because they will know your wishes and be able to honor them.



### I cannot pick just one person to make decisions for me. We make decisions as a family.

It can be hard to choose just one person to make medical decisions for you. The person you assign to make decisions for you is called your Healthcare Agent.

Colorado law requires for everyone 18 years and older to put in writing who will speak on their behalf if they need medical care and they cannot express their needs. This is called a Medical Durable Power of Attorney (MDPOA).

If a person does not complete a MDPOA, then the doctor must gather all "interested parties." They must then decide who the best person is to make decisions for you. This can be very hard for families. It can create long-lasting resentments and conflict.

Choosing someone ahead of time helps everyone involved in your care support your wishes. It can also support the person you have chosen to make decisions for you.

### I don't want to take pain medicine and get addicted.

Talk with your doctor about your concerns. Share your worries so that you and your doctor can make the best plan to take care of your symptoms. When your symptoms are controlled, you will be able to enjoy and take care of your family.

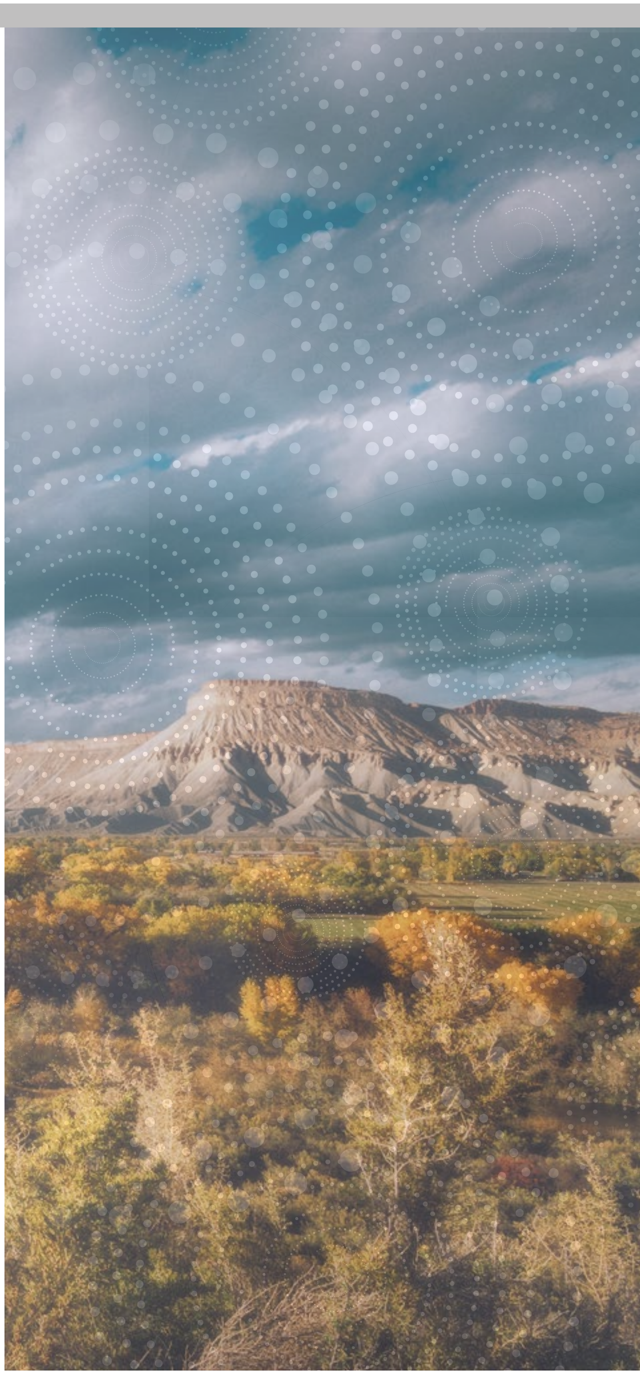
### Will the palliative care team replace the care my family members give me?

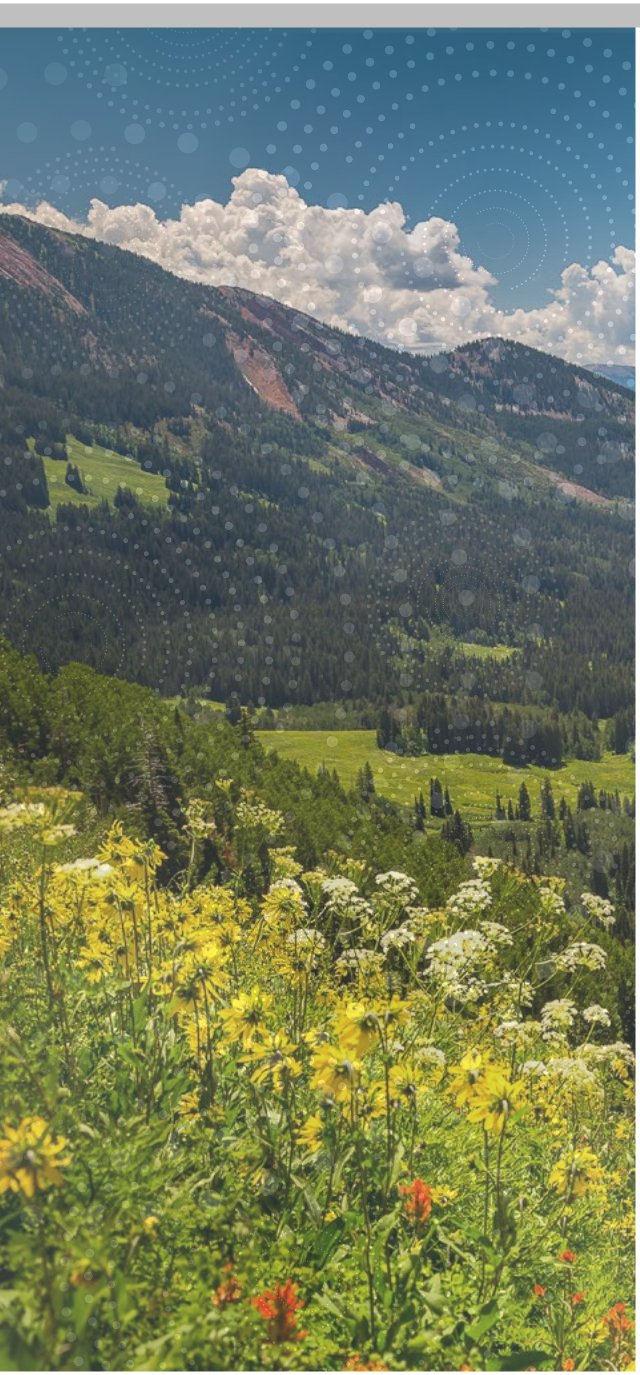
No. The care your family gives you will always be there. The palliative care team supports the care your family has already been giving you.

This team works together with your family. The team can help find more community resources you. They also may want to assist with physical, emotional, or spiritual concerns if you want. These resources will never take away the love and care that your family gives you.

Palliative care also provides support for your family, so they can provide the best possible care for you.

The palliative care team values family members and the support they give you. The team is another pair of hands to enhance your quality of life as well as that of your family.





## PALLIATIVE CARE FOR CHILDREN

You may have a seriously ill child or a child living with a life-long or progressive disease. If you do, palliative care can be a great resource for you and your family.

It can help you make the most of this time. It will give you an extra layer of support. It will help you to decide what is most important for your child and your family.

### What is Pediatric Palliative Care?

Pediatric Palliative Care and Pediatric Hospice Care are often a key part of medical care for children who have life-threatening conditions or are in need of end-of-life care.

Pediatric Palliative Care and Pediatric Hospice Care aims to:

- Relieve suffering
- Improve quality of life
- Facilitate informed decision-making
- Assist in care coordination between clinicians and across sites of care

*American Academy of Pediatrics Policy Statement*

## Goals of Pediatric Palliative Care are to:

- Relieve suffering, ease pain, and help with symptom management, as well as improve quality of life for the child.
- Give emotional and social support.
- Offer help with making medical decisions.
- Help children decrease the amount of time they spend in the hospital by linking families with resources.
- Help the child's healthcare team work together to support the child's and family's goals of care.

## Some questions to ask yourself about your child are:

- What makes your child happy?
- What does a good day for your child look like?
- What goals have you and your child set, and how can you reach them?
- What is most important to you for your child's quality of life?

## Pediatric Medicaid Waivers

If your child has Medicaid this is important for you to know.

Colorado Medicaid offers a few waivers. These waivers are add-on coverage to help support children who have extreme healthcare needs.

Unlike regular Medicaid, these waivers are based on the child's income. So, most children will qualify.

You can get access to these waivers through the Single Entry Point in your county. To learn more, call your county health department here: https://cdphe.colorado.gov/public-information/find-your-local-public-health-agency.

These are the types of Medicaid support you may be able to access for your child:

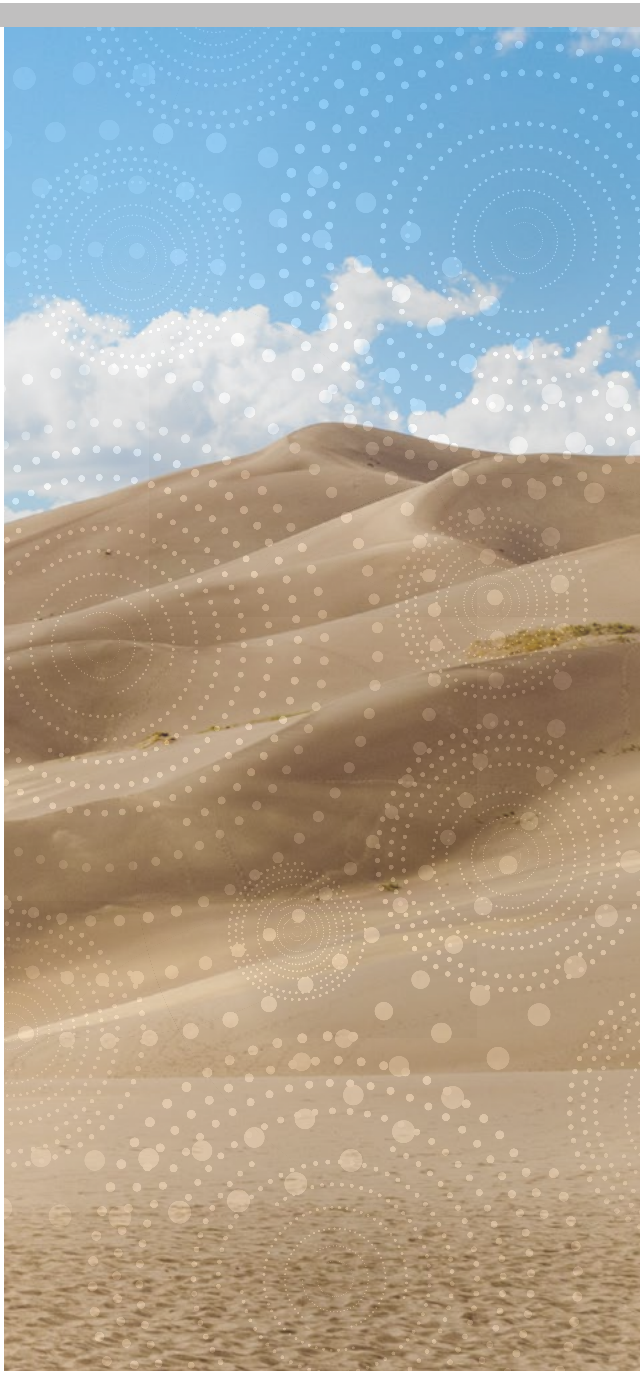
- Children with Life Limiting Illness Waiver: This is for children who may die before the age of 21. It provides supportive care in the home. Some hospices provide palliative care services at home. This may include art therapy, massage, and nursing. This waiver is what you need to pay for those services. It also helps cover end of life hospice care for families who want to continue treating the illness.
- Children's Extensive Support program (CES)
- Home and Community Based Services (HCBS)

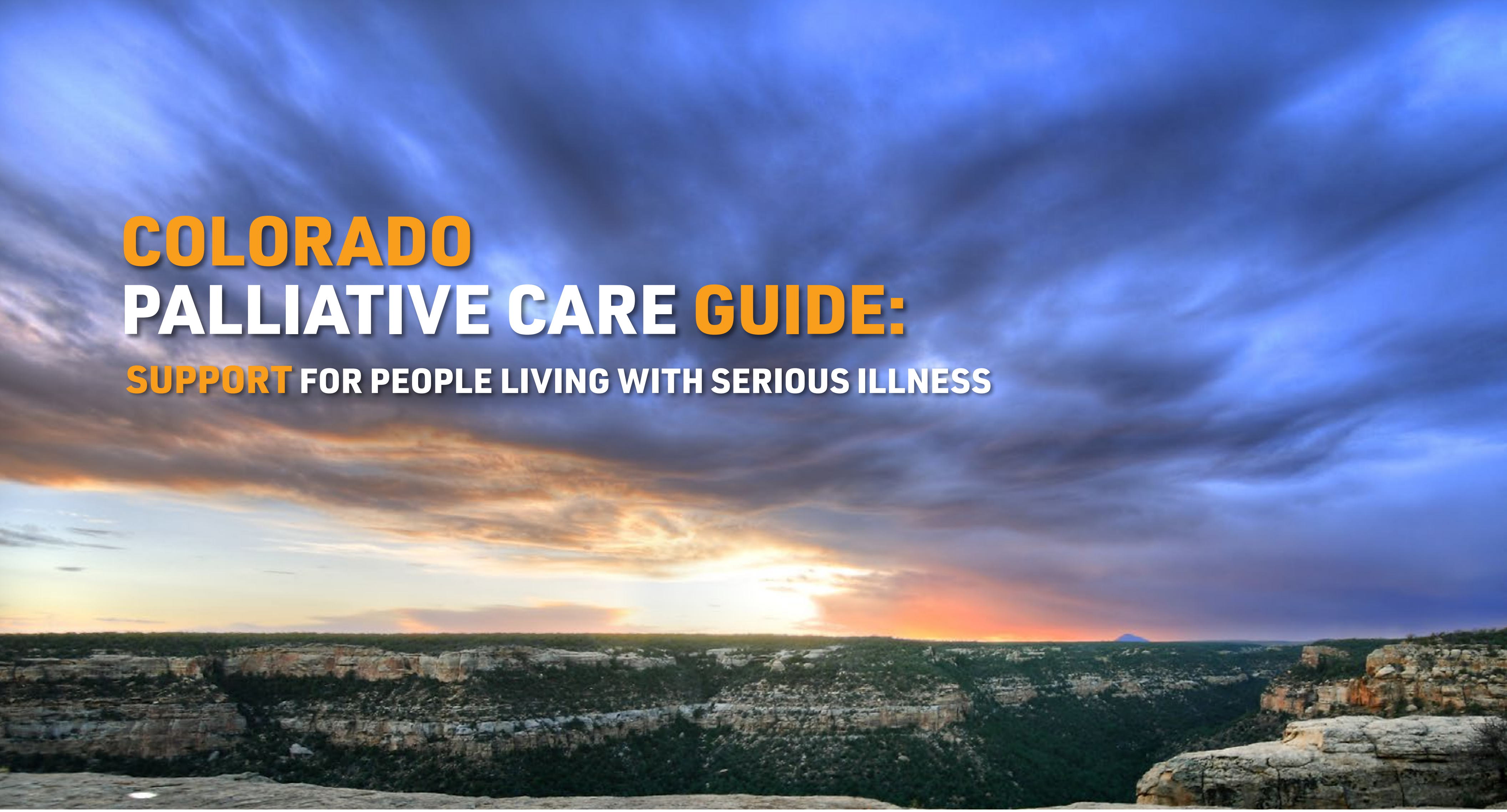
## Pediatric Concurrent Care

Because of the Affordable Care Act, children under the age of 21 on Medicaid can receive concurrent care.

This allows the child to receive both curative treatments and comfort care at the same time. It allows families to have support for their child that aligns with the family and child's goals of care.

This means that children with cancer could keep receiving chemotherapy or radiation to prolong life while also having hospice nurses in their home to make sure they are not suffering.





# 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

## 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.

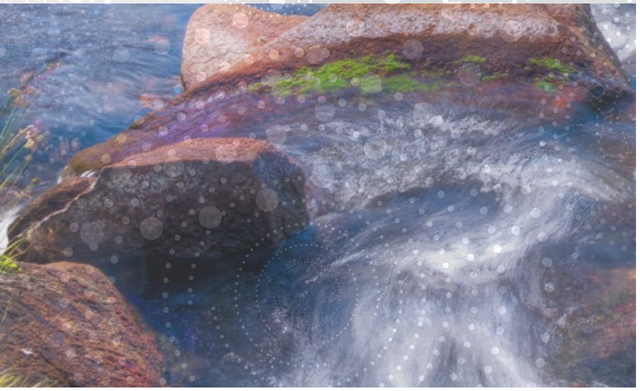
Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment.

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

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

**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.



## 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.

## 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

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

- 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.

| | ADVANCE DIRECTIVE | MOST (Medical Orders for Scope of Treatment) |
|---|---|---|
| **Who is it for?** | Everyone 18 and older. | People with a serious illness or who are very old and frail. |
| **What kind of document is it?** | It is a legal document. | It is a medical order. |
| **Who signs it?** | 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. |
| **Do I need a lawyer?** | No. | No. |
| **Who keeps the form?** | 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. |
| **Can I change the form if I change my mind**? | 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. |
| **What if there is a medical emergency and I cannot speak for myself?** | 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:

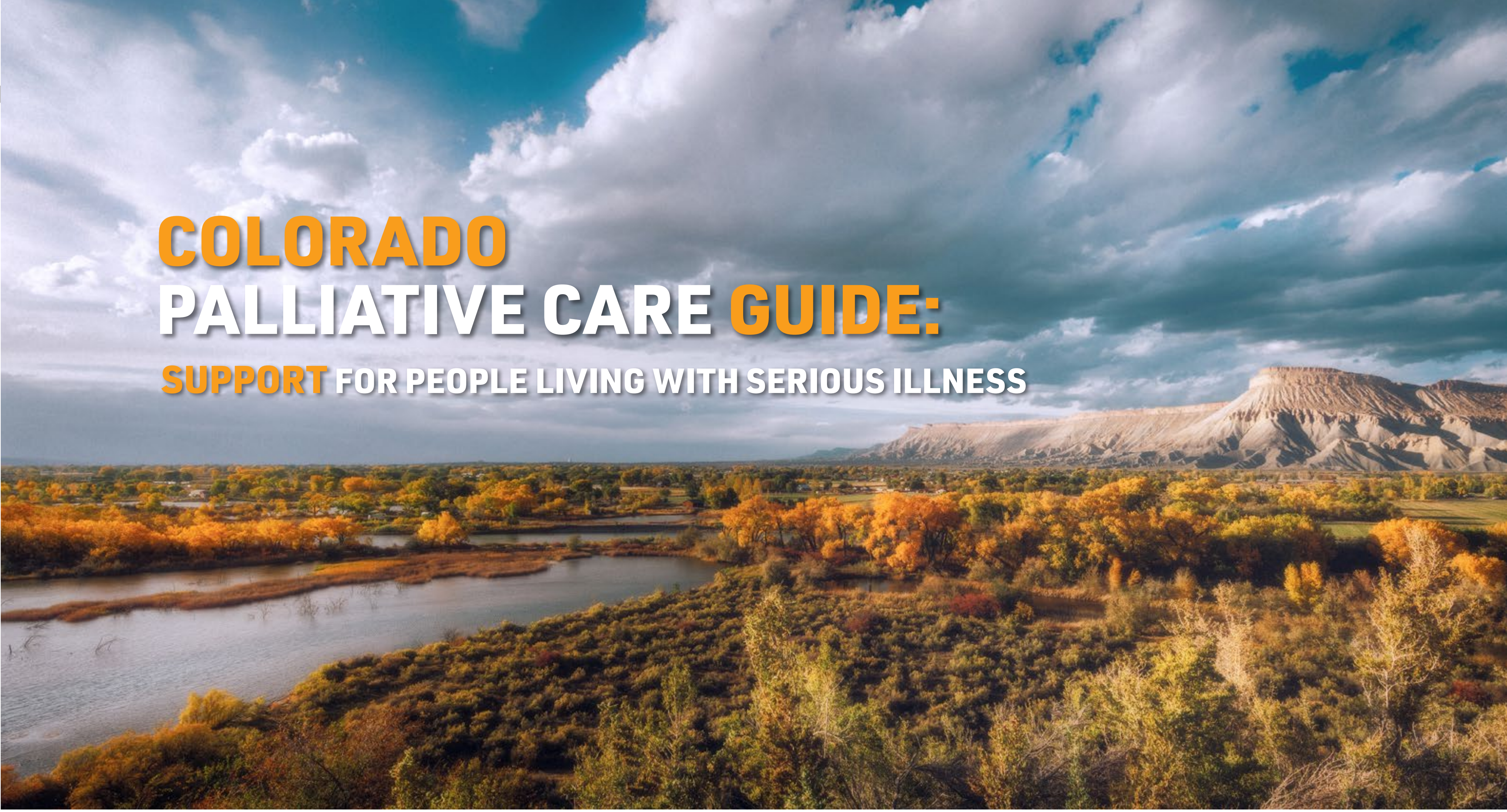
- Acupuncture involves inserting tiny needles into the skin to stimulate specific parts of your body. It may help manage pain and other symptoms.
- Massage therapy is a treatment where the expert rubs, taps, and strokes the soft tissues of the body. It may help you relax as well as relieve stress and 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.



# 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

**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.

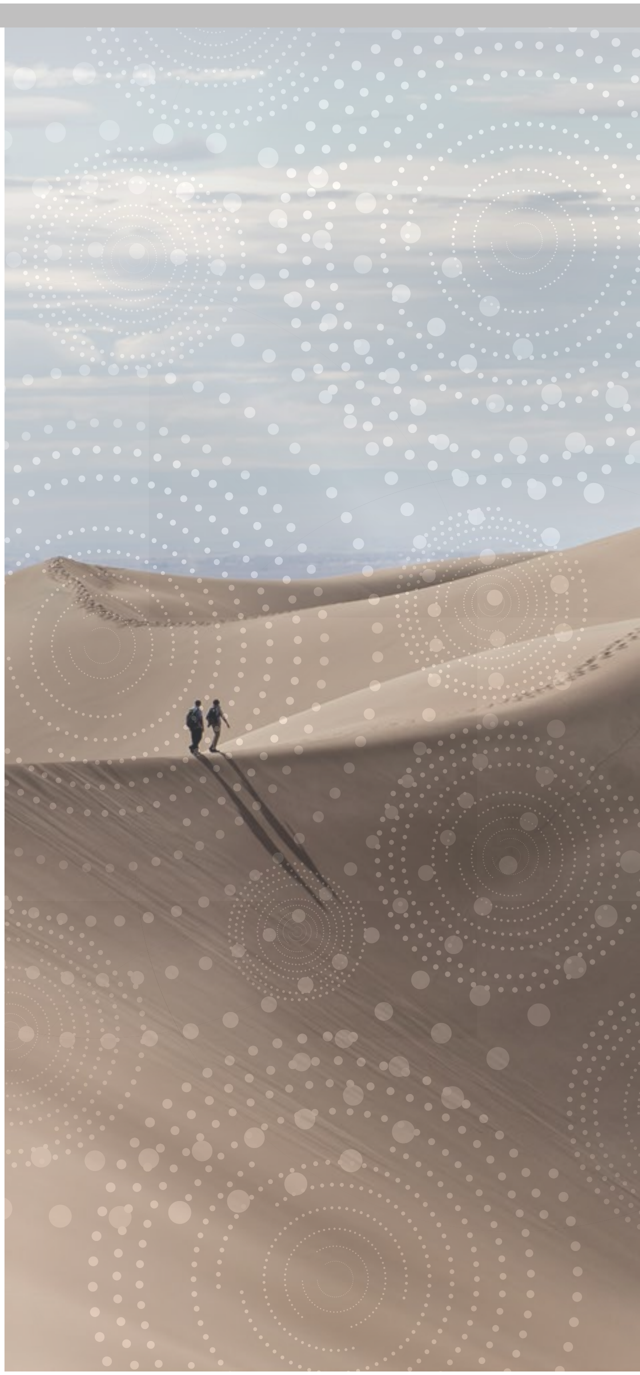
## Common concerns to discuss with your palliative care team or doctor

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.

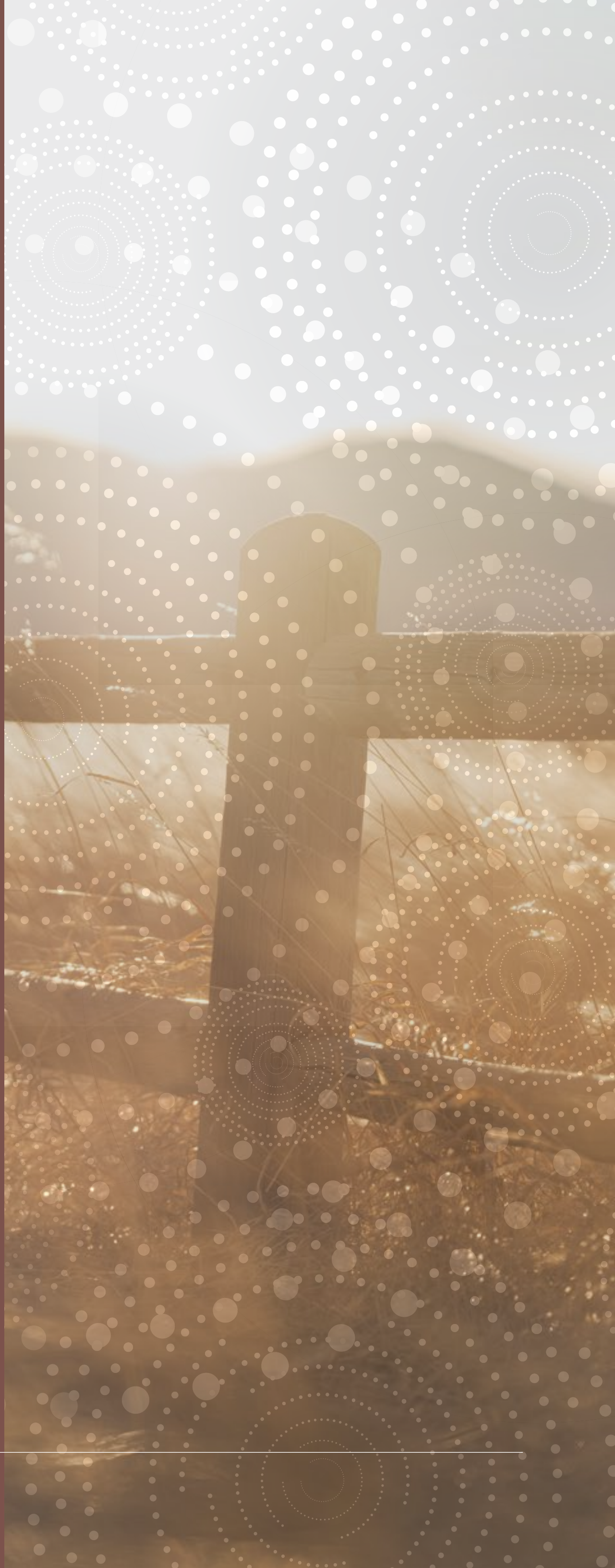
## What you can do to help yourself:

- 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.

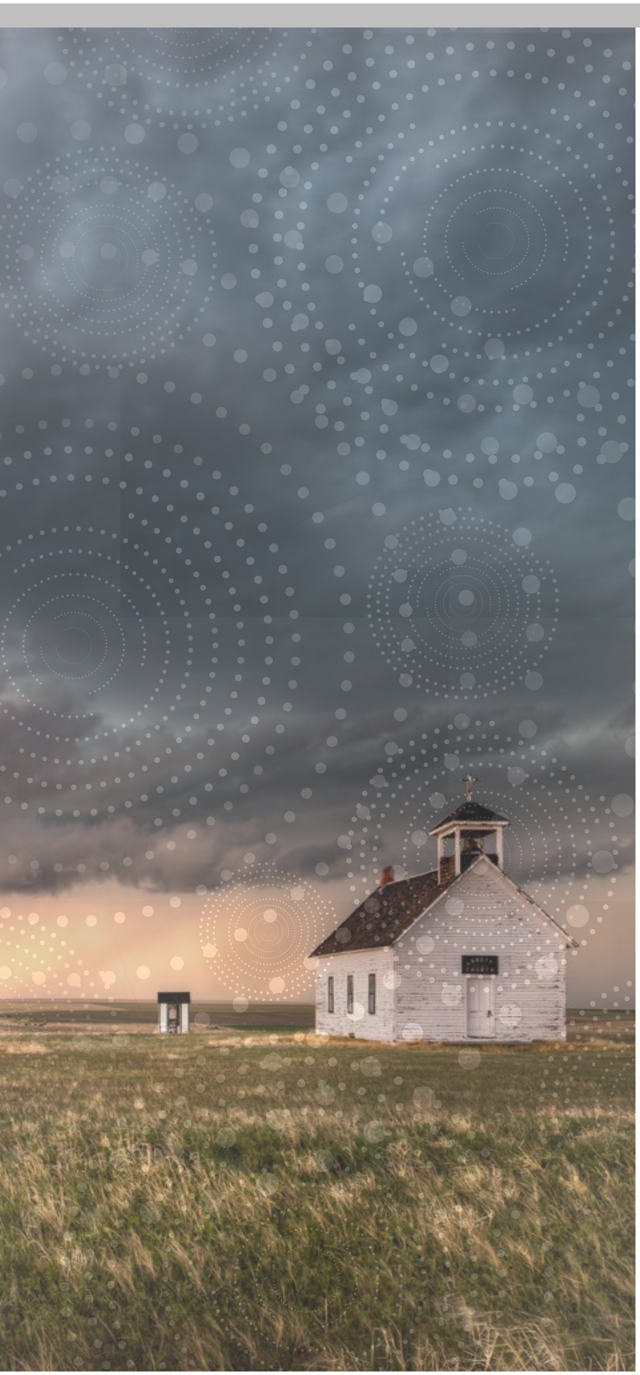
### Common concerns to discuss with your palliative care team or doctor

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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