

# New Jersey Palliative Care Guide

Support for people with serious illness

This guide is for you  
and your loved ones

**Home Care** Association  
& Hospice *of NJ*

[www.homecaresnj.org](http://www.homecaresnj.org)

# NEW JERSEY PALLIATIVE CARE GUIDE

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

Introduction \_\_\_\_\_ 2  
Questions You May Have Along the Way \_\_\_\_\_ 3  
Palliative Care \_\_\_\_\_ 4  
What to Expect Early in this Time of Serious Illness \_\_\_\_\_ 6  
Advanced Directives and Durable Power of Attorney for Health Care \_\_\_\_\_ 7  
Financial Matters \_\_\_\_\_ 10  
Culture and Diversity Issues \_\_\_\_\_ 10  
Palliative Care for Children \_\_\_\_\_ 12

## SECTION 2: LIVING WITH SERIOUS ILLNESS

Meeting Your Palliative Care Team \_\_\_\_\_ 14  
If You are a Caregiver, How You Can Offer Support \_\_\_\_\_ 15  
Practitioner Orders for Life-Sustaining Treatment (POLST) \_\_\_\_\_ 16  
Therapies to Manage Pain and Symptoms \_\_\_\_\_ 17

## SECTION 3: CHANGING GOALS OF CARE

What If You Recover from Serious Illness? \_\_\_\_\_ 18  
What If Your Illness Advances? \_\_\_\_\_ 19  
Roles and Needs of Loved Ones \_\_\_\_\_ 21  
Acknowledgments \_\_\_\_\_ 22

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

## INTRODUCTION

The Home Care & Hospice Association of New Jersey is pleased to share with you this *New Jersey 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 coordinate your care with others
- Care in different settings and with different doctors
- Costly medicines and treatments
- Access to and cost of food
- More responsibilities for loved ones

A person facing serious illness may go through many forms of grief. Grief 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
- They have lost the ability to communicate with your loved one

If a person ignores grief, the experience of illness can be even worse.

### TO LEARN MORE:

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

If you want to learn more, you can go to the Center to Advance Palliative Care webpage: <https://www.capc.org/>.

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

**You can find a list of palliative care providers in New Jersey at:**

<https://getpalliativecare.org/provider-directory/>

With palliative care, a team will help support you through your serious illness. The team 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.

If you are a veteran, check with the U.S. Department of Veterans Affairs to see if you can receive palliative care benefits.

# 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 should I ask?
- Where can I get more information about my specific symptoms and treatment options?
- What do I need to consider if I become seriously ill?

## Diagnosis

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

A **healthcare agent** is someone whom you have chosen to make medical decisions for you if you are not able to express those wishes for yourself.

## 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 dying well?
- How can I make sure my wishes about the end of my life are expressed and followed?

# 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 level of support.

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

## Who is palliative care for?

Palliative care is for everyone with serious illness. It is appropriate at any age and at any stage of a serious illness and can be provided together with curative treatment. It is for people of all races, ethnicities, religions or financial status. It is about keeping you at the center of care. It makes sure the plan of care and the way care is given is tailored to meet your needs.

## Is palliative care like hospice?

Palliative care and hospice have some similarities. They are both focused on the patient's and family's quality of life and can provide many of the same services – medical, nursing, social work and chaplaincy.

Hospice is available only to patients who are terminally ill and have a life expectancy of six months or less. Hospice patients may not continue receiving curative treatment for their terminal illness.

Palliative care is available to patients at any point in their disease process. They need not be terminally ill and may continue to receive treatment for their illness(es).

## 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* 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?

Palliative care can begin with your primary care doctor or specialist. It can take place in your home, the hospital or a clinic – depending on how that provider operates. Be sure to ask where care would be provided.

The palliative care team works with your current doctor -- it does not replace your doctor. Patients unable to travel may be able to receive services through telehealth. Ask your doctor about this.

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

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

## Who is on a palliative care team?

A team may include:

- Doctors – physicians, nurse practitioners and/or physician assistants
- Registered nurses
- Social workers
- Chaplains

The team members work together so that they all:

- Understand your goals of care
- Are aware of how the team will contribute to help meet these goals

Palliative care team members might be part of:

- Clinics
- Cancer clinics
- Hospitals
- Palliative care and hospice organizations
- Home health agencies
- Other organizations in the community, such as rural health organizations or PACE (Program of All-Inclusive Care for the Elderly)

## 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? Are these decisions final?
- How do I identify what is most important to me?
- Will I still be able to walk/speak/read?
- What do I tell other people? How and when should I tell them?
- Can I take part in a big family event coming up?
- How will I manage my daily life now and in the future? This includes my job, family and more.

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

**Chaplains** work with you to examine what values are important to you and help you find meaning in life. They provide these supports and counseling:

- Spiritual
- Pastoral
- Emotional
- Grief

**Goals of Care** means medical care you want based on your values and what is important to you.

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?
- Is there any specific goal or task you would like to achieve?
- 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 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 which treatments 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 ask, “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 wishes known. You do this through a Durable Power of Attorney for Health Care. For the correct form, go here:

[https://www.nj.gov/health/advancedirective/documents/proxy\\_directive.pdf](https://www.nj.gov/health/advancedirective/documents/proxy_directive.pdf)

What else can you do for yourself?

- 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, such as dementia and Parkinson’s, change your ability to have conversations. 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 for 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.

## WHAT YOU CAN DO FOR YOUR LOVED ONES

Here's how you can help your loved ones during this time:

- Fill out a Durable Power of Attorney for Health Care. It's a gift to your loved ones to make this time easier for them. They will then 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 with your care decisions. See Advance Directives (*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 others 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 and social media passwords
- Organize your legal and financial paperwork. 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.

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

In a **Durable Power of Attorney for Health Care**, you appoint your healthcare proxy/agent. This should be someone you trust to speak for you if you are unable to speak for yourself due to illness or injury.

## ADVANCE DIRECTIVES AND DURABLE POWER OF ATTORNEY FOR HEALTH CARE

It is important to appoint a healthcare decision maker. Read about this in the Durable Power of Attorney for Health Care (POAHC) section below and in the Practitioner's Orders for Life Sustaining Treatment form in Section 2. You can find the New Jersey Power of Attorney for Health Care form here:

[https://www.nj.gov/health/advancedirective/documents/proxy\\_directive.pdf](https://www.nj.gov/health/advancedirective/documents/proxy_directive.pdf)

We do not share about other advance care planning documents in this Guide. These include the Living Will, Five Wishes and the Out-of-Hospital Do Not Resuscitate (OOHDNR) form. If you want to learn more about these, you can go to:

<https://www.state.nj.us/health/advancedirective/ad/forums-faqs/>

<https://www.fivewishes.org/>

<https://www.njha.com/polst/>

[http://www.njha.com/media/33220/outofhospital\\_dnr\\_form.pdf](http://www.njha.com/media/33220/outofhospital_dnr_form.pdf)

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.

These include:

- a Durable Power of Attorney for Health Care
- a Living Will
- a Five Wishes
- a POLST (Practitioner Orders for Life Sustaining Treatment)

Making healthcare decisions for yourself or for someone who is not able to do so can be overwhelming. 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**

What happens if or when you are not able to make your own medical and financial decisions? Whom would you trust to make them? It is important to think about and know what your wishes are. This is so your loved ones and doctors can honor those wishes.

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 Durable Power of Attorney for Health Care (DPAHC).

Use this checklist to make sure you have healthcare and financial matters in place. Do it now, before you have serious illness advances or a healthcare crisis. Find a family member, close friend or an 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 healthcare changes, divorce, a move, or when your healthcare proxy is no longer able to speak for you.

Put important papers on the 'fridge, such as the DPAHC, POLST and other care planning forms. This is because that's where first responders will 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 your doctors, so they can add them to your medical files. Have them entered into your hospital's medical record, if there is a particular hospital you go to.

Let your doctor know you have a signed DPAHC or decision maker.

Reduce anxiety by planning ahead for funeral and burial plans.

A few states, including New Jersey, do not have laws stating who can act in an incapacitated person's place if no Durable Power of Attorney for Health Care (DPAHC) exists.

Without the DPAHC, your family may have to go to court to get a guardian appointed.

Even in states with laws establishing a "decision-making tree," family members may disagree over treatment and end up in court, asking the court to appoint a guardian.

Guardianship is a legal relationship between a competent adult (the "guardian") and a person who because of incapacity is no longer able to take care of his or her own affairs (the "ward"). The guardian can be authorized to make legal, financial and healthcare decisions for the ward. The guardianship process is expensive, time consuming and very restrictive, so it is almost always a last resort.

**Creating a DPAHC saves money, time and conflict.** (adapted from [www.elderlawanswers.com](http://www.elderlawanswers.com))

## THE DIFFERENCE BETWEEN THE ADVANCE DIRECTIVE AND POLST

A POLST form is the Practitioner Order for Life Sustaining Treatment. The Advance Directive and the POLST are very different. Still, it's easy to confuse the two. This chart shows you the differences.

	<b>ADVANCE DIRECTIVE</b>	<b>POLST (Practitioner Orders for Life Sustaining Treatment)</b>
Who is it for?	Everyone 18 and older.	People with a serious illness or who are very old or 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 healthcare representative signs it and witnesses.	Your doctor, physician assistant or advance practice nurse fills it out with your input and the doctor 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 healthcare representative and your doctor.	You keep the original, signed POLST form. It is recommended that you post your POLST form in your home, at a readily visible spot like a refrigerator door. Your doctor should keep copies of your POLST form with your medical record.
Can I change the form if I change my mind?	Yes. You should tear up the old one once the new one is signed. Post the new one on the 'fridge and give copies to your doctor(s).	Yes. You can ask for an appointment with your doctor to change it. You cannot change it without a physician's signature.
What if there is a medical emergency and I cannot speak for myself?	Your healthcare representative speaks for you and honors your wishes.	The ambulance staff, hospital staff and doctors will look for the POLST form and follow it.

What happens if you do not choose a healthcare proxy?

### **Proxy Medical Decision-Maker**

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

If, however, you do not choose a healthcare proxy and document that choice, you may not know who will be making healthcare decisions for you. Unfortunately, New Jersey is one of the few states where there is no "decision-making tree" specifying who makes medical decisions for people who are unable to make decisions for themselves and there is no Durable Power of Attorney for Health Care. In these situations, the physician will (extra-legally) ask family members to make decisions, or – if the law is to be strictly followed – the family must follow the costly and time consuming process of having a guardian appointed.

The process of appointing a guardian can take time, cost thousands of dollars 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. Further, if one family member does not agree with the decisions being made, they could may

petition the court to have a guardian appointed and slow the process even more. Choosing a healthcare proxy avoids these complications.

If you regain the ability to make decisions for yourself, the proxy authority is cancelled.

## 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 filing out a special form. It is called a Durable Power of Attorney This person may or may not be the same person whom you choose as your Durable Power of Attorney for Health Care.

**New Jersey's Durable Power of Attorney** is a document through which you name someone to make your financial decisions if you are unable to do so.

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

## CULTURAL AND DIVERSITY ISSUES

Living with a serious illness or 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 or identity
- Other factors

**Cultural minority group** refers to racial, ethnic, gender, physical characteristic(s) or sexual orientation/identity that may single out a person for unequal treatment.

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 heard and respected

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

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

- What is important to include in making decisions?

- Do you come from a culture where each person makes their own decisions? 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 the provider know who should receive 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 who respects you as a person are:
  - Can 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 your team 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.
- Sometimes people are not comfortable talking about serious illness 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.

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

Family interpreters may seem 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 have a 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 (in advance of your appointment, if possible). It is your right. 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 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 need based on your values and what matters to you most
- Helping to address the fears and 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. Can it 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 proxy or healthcare agent. If your family resists identifying just one person to make decisions, explain that the family can agree on a single option and the healthcare agent “just signs the form” to document the decision.

Choosing someone ahead of time helps everyone providing care to support your wishes. It can even 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 doctors about your concerns. Share your worries so that your doctor can make the best plan to take care of your symptoms. When your symptoms are controlled, you will be able to enjoy life more 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 members have already been giving you.

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

The palliative care team values family members and the support they give you. This 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 living with a lifelong 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 decide what is most important for you 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 aim to:

- Relieve suffering

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

The American Academy of Pediatrics supports the use of palliative care and hospice for appropriate children.

**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?

If you are on New Jersey Medicaid, your child can receive curative treatment and hospice care simultaneously – this relieves the family from making a hard choice between the two (for example., choosing between chemotherapy and hospice for a child with cancer). Please check with your family's private insurer to see if your policy offers the same simultaneous benefit.

## SECTION 2: LIVING WITH SERIOUS ILLNESS

What is palliative care?

Palliative care is specialized medical treatment 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 of a serious illness and can be provided together with curative treatment.

If you have a health plan, review your benefits. Be sure to review palliative care benefits.

If you are a veteran, check with U.S. Department of 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 team member or team:

- Define who you are as a person, your values and how these affect your healthcare decisions.
- Discuss your diagnosis, treatment options and what you hope treatment can achieve.
- Share about your symptoms.
- Learn how your palliative care team can 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 meet with them:

Do not assume that your palliative care team knows what you do or do not understand. You can help by offering your own sense of that. For example, you can say:

- "I understand that, as my disease progresses, I may face symptoms like..."
- "I am not sure when I should call for help."
- "I do not understand my treatment choices."

Ask for 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 refuse 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 for your symptoms. These include:

- Acupuncture
- Reiki
- Massage therapy
- Herbal alternatives
- Other

Other therapies can provide comfort. These include:

- Pet therapy
- Music therapy
- Art therapy

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

- Make sure you have filled out your advance care documents. Make sure you have talked with all your doctors about them.
- Before the appointment, write your questions down in a notebook.
- There may not be time to cover all 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 questions or need to travel a long way to the clinic or office. Your doctor may or may not be able to offer extra time, rather than have you make an extra trip.
  - 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 that this is *your* care. Your concerns and values should guide the decisions you make.

## **IF YOU ARE A CAREGIVER, HERE'S HOW YOU CAN OFFER SUPPORT**

- Ask what the patient wants and needs. 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 on healthcare appointments and take notes.
- Discuss who to tell about the diagnosis and what 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 that case, you can suggest a healthcare appointment.
- Ask open-ended questions to start conversations – for example, “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 experiences and talk to your doctors and loved ones about your feelings.

## **PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST) FORM**

There is a form called POLST, or Practitioner Orders for Life-Sustaining Treatment. Your doctor might discuss this form with you. Or, you can ask your doctor whether you should have a POLST.

Here are some questions and answers about the POLST form.

### **What is the POLST form for?**

It is for people who:

- Have a serious medical 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 POLST form is a medical order that your doctor signs. It states what your wishes would be if you have a medical emergency.

You complete the form with your doctor. Then your doctor signs it. You keep the signed POLST form. It is recommended that you post the POLST in a visible place in your home, like the refrigerator. Your doctor should keep a copy of the signed POLST form in your medical record.

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

The form consists of six parts:

- Goals of Care
- Options for Medical Treatment – the person chooses between Full Treatment, Limited Treatment and Symptom Treatment Only
- Artificially Administered Fluids and Nutrition – the person chooses between none, long-term artificial nutrition and a short-term trial period
- Cardiopulmonary Resuscitation (do not attempt/attempt resuscitation) / Airway Management (intubate/do not intubate)
- Authorization for the person's surrogate decision-maker to modify or revoke the POLST form – the person grants that authority or not
- Signatures – of the person and the physician/advance practice nurse/physician assistant. This section also includes contact information for a surrogate decision maker

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

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

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

Yes. You have the right to change your choices on the POLST form at any time in consultation with your doctor.

A doctor should review the form with you every so often. This is to know if it still accurately reflects your choices now. If you have changed any of your choices, the doctor can change the form or complete a new POLST form.

When the doctor reviews this with you, the doctor will then mark a new date and signature. Or the doctor may complete a new POLST 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 the POLST form. Or you can ask to make changes at your next healthcare visit. Do not make changes independent of your doctor – it will invalidate the form.

### **Is the POLST form the same thing as an advance directive?**

No. They are not the same. The POLST form is a medical order that you and your doctor sign. The advance directive is a legal form that you sign. The POLST is a form that supplements your advance directive. Earlier in this Guide (*page 9*), there is a table explaining the differences between an advance directive and a POLST form.

## **THERAPIES TO MANAGE PAIN AND SYMPTOMS**

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

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

- **Gentle exercise and time spent in nature** can relax the mind and emotions. They may relieve stress and lower 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 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 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 or sleeping well. The therapies listed above may help relieve these symptoms as well.

Discuss any of these types of therapies with your care team before starting the therapy. These therapies can often be helpful, but they can also interact with other medical treatments or, in a few cases, they can pose added risks.

## SECTION 3: CHANGING GOALS OF 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.

**Quality of life** means you are able to enjoy your activities of life and enjoy life based on your

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

### WHAT IF YOU RECOVER FROM SERIOUS ILLNESS?

Some people will recover from serious illness. Others may have a condition that becomes stable over time. In this section, we offer support for people who 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 or doctors. You may have other questions. You should write them down in the days before an appointment and discuss them with your doctor.

- 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? 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 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, especially with symptoms from the after-effects of treatment.

#### 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 that you went through more than when you were in the middle of them. Grief is a normal part of thinking about what you went through.
- Talk to your doctor about what to expect and possible treatments going forward.
- Volunteer or find other 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 someone with serious illness, here are some things you can do to support them and yourself.

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

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

## WHAT IF YOUR ILLNESS ADVANCES?

Sometimes your illness or healthcare 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 discuss with your team members or doctor. 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 proxy prepared to follow my wishes if I become unable to speak for myself?
- What do I do if my 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 do the things you normally do. Fatigue is a large part of many illnesses and can be frustrating. This is sometimes called adjusting to the “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 doctor what to expect as your disease or condition advances. You have the right to know 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 receiving curative treatments. Ask your doctor to make a referral to a palliative care team.

Make sure all your doctors know of your wishes and will honor them. These people may include doctors and others who 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 and pets

Consider working with an occupational therapist. They can recommend medical equipment or supplies that can 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.

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

Tell loved ones how you are doing and what you need.

Know that those around you may be grieving. If you are willing, talk to them about their feelings. If you are not, invite them to find help for themselves.

## Hospice

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

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

People can get hospice care if they have a terminal illness and their doctor believes they have six months or less to live if their illness runs its natural course. Hospice may continue beyond the six months if the doctor still believes the illness will be terminal within six months. Patients can leave (“revoke”) hospice at any time, with or without a reason, and may return at any time.

The hospice team customizes its plan of care for each patient. Services will include physician oversight, nursing care, medical social services, various types of counseling and medications/equipment related to the terminal illness. Services may also include visits by aides several days per week to help with patient-related housekeeping and volunteers to provide companionship, give families a break, run errands, etc. Bereavement (grief) counseling will be offered for at least one year after the patient dies.

Hospice is covered by Medicare, Medicaid and most private insurers.

Hospice is often provided in the home. It may also be provided in nursing homes, assisted livings and other settings where the patient lives. Residents of nursing homes on Medicaid may have their room and board R&B covered by Medicaid when on hospice. There are also several “hospice houses” in New Jersey – these are not considered nursing homes.. Patients in these “hospice houses” may be required to pay an R&B charge beyond the actual hospice services.

You can ask for a free, no-obligation hospice care evaluation (an “assessment”) if you are concerned about your prognosis. Learn more about hospice at [www.homecarenj.org](http://www.homecarenj.org) or [www.nhpco.org](http://www.nhpco.org).

People often say they wish they had started hospice earlier. Learn how hospice can help you.

## ROLES AND NEEDS FOR LOVED ONES

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

- Allow them to talk about their hopes and fears. Allow for moments of silence.
- Help record questions to ask the doctor. Take notes from the doctor’s reply.
- 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 and try to follow through.

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 provides someone to step in to help your loved ones so they can get a break to rest or attend to other needs.
- Work to find balance in your life. Try not to give your loved one’s illness the total focus of your life. Pay attention to cues that the loved one, too, 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 the illness may change. Think about making a plan for more services if needs increase. Know that your relationship with the patient may change too.
- It is normal to start to grieve the loss of a loved one before they are no longer there. Ask your team social worker or chaplain for grief resources and support.

The person who provides care for you is called a **caregiver**.

**Respite care** provides a temporary caregiver who can stand in for a regular caregiver and provide them with a break to rest or do other chores.

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

To find palliative care providers, go to [www.getpalliativecare.org](http://www.getpalliativecare.org) – click on “Access the Provider Directory.”

Please check with your insurance provider about whether it covers palliative care. Your palliative care team may know that as well. If you are a veteran, check with the U. S. Department of Veterans Affairs.

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