

# Let's talk



## **Discuss, decide, document** your wishes for end-of-life care

### **Advance Care Planning Guidebook**

Do your family and healthcare providers know your wishes for end-of-life care? This guide will help make sure you get **the care you need and no less, and the care you want and no more.**



Goals of Care Coalition  
of New Jersey

Without an advance care plan, healthcare providers are required to do everything possible in an attempt to save your life. This aggressive medical care is often unwanted and may be difficult for patients and families.

- ▶ Did you know, **patients near the end of life in NJ are treated with more intense medical care than any other state in the US?**
- ▶ There are many reasons why patients may receive unwanted care but a key one is **a lack of communication between patients, families and healthcare providers.**

**90%** of people say that talking with their loved ones about end-of-life care is important

**27%** have actually done so<sup>1</sup>

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**80%** of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life

**7%** report having had that conversation with their doctor<sup>2</sup>

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**82%** of people say it's important to put their wishes in writing

**23%** of people have actually done it<sup>3</sup>

1 The Conversation Project  
National Survey 2013

2 Survey of Californians  
by CAHF

3 Survey of Californians  
by CAHF 2012



# Why is advance care planning so important?



An advance care plan is a document that explains your wishes to loved ones and others who may need to make medical decisions for you if you are unable to do so yourself. This plan helps make sure that your family and healthcare providers all understand your wishes when it comes to your care.

An advance care plan would only be used if you cannot speak for yourself and you can change it at any time. It's never too early to create an advance care plan and there's rarely a good reason to wait.

This guidebook will lead you through the process of advance care planning as you discuss, decide, and document your wishes for care at the end of your life.

- ▶ **Discuss:** it's helpful to talk with your family, friends, or someone you trust (clergy, healthcare provider, etc.) to help clarify what's important to you. Having these conversations will give your loved ones the confidence to make decisions on your behalf if you are unable to do so yourself — making a difficult time somewhat easier.
- ▶ **Decide:** it's time to get all of the facts and review them with your healthcare providers and family so that you may make some decisions about your future. You'll need to decide on who will be your medical decision maker or Healthcare Proxy and what types of treatment you do and do not want.
- ▶ **Document:** it's important to document your decisions about a Healthcare Proxy, treatment, and any other care you'd like to receive at the end of life to make sure your plans are carried out.

# Discuss



Discussing your wishes will help you identify what matters most and help your loved ones and healthcare providers to provide the treatment that you want to receive.

People can be uncomfortable discussing serious medical concerns, especially relating to end-of-life care. Patients and family members may feel like they're giving up hope. Healthcare providers may fear it sounds like they are not doing all they can for their patients. However, the reality is that **it's important to have these discussions to make sure people truly understand your wishes.**

Here are some commonly held beliefs that are usually not accurate.

**MYTH:**  
“My family  
will know  
what to do.”

► **FACT:** Your family may have some general ideas about care but may not know your specific wishes. It's important to have these conversations so your family and caregivers will know what to do on your behalf. These discussions may help avoid conflict within a family since all members may not otherwise agree on what you would want.

**MYTH:**  
“My doctor  
will tell me  
when it's time  
to think about  
end-of-life  
planning.”

► **FACT:** During a typical office visit there may not be enough time to have a thoughtful conversation about this important topic. Also, not all healthcare providers are comfortable talking about end-of-life planning and may not start the conversation.

Discussing your wishes with your family or people you trust will prepare you to have these conversations with your healthcare providers.

**MYTH:**  
“It will be too hard for my family to have a discussion about end-of-life care.”

➤ **FACT:** Your family may find these conversations difficult but they also may take comfort in knowing what treatment you do and do not want to receive. Having these conversations now will make your wishes more clear and may make it easier to make difficult medical decisions in the midst of a medical crisis.

## Things to consider

- How important is it for you to remain comfortable and avoid unpleasant treatments?
- Do you have fears about dying? If so, what are they?
- Would you prefer to die at home, in a hospice, or in the hospital?
- What would be your priorities as you near death? For example, do you want to be surrounded by family or friends? Do you want to be free of pain and anxiety? Are there religious rites or spiritual concerns you want to address?

### Before you begin the conversation

As you consider what is most important to you, focus on your life not your disease. However serious the medical issue you are facing may be, decisions about quality and length of life are life-affirming decisions, and they should follow your personal values, beliefs, and goals.



# Decide

After you've thought about your wishes and discussed them with your family and others, it's time to decide on the types of treatment you do and do not want to receive. Making these decisions now will ensure that future medical decisions follow your personal wishes and are less burdensome on your family.



## Decide on a healthcare proxy

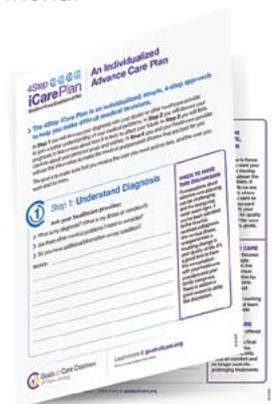
A Healthcare Proxy is the person you choose to make medical decisions for you if you are unable to do so yourself. This person will talk to your healthcare providers and make decisions about treatment that follows your wishes. A proxy should be able to speak on your behalf and make decisions as circumstances change. He or she should be someone you trust, such as a family member, spouse, or trusted friend.

## Use the 4Step iCare Plan

After you've taken the time to consider your wishes, you'll be more prepared to discuss them with your healthcare providers. As a result, they will be better able to work with you to determine which treatments will match your goals of care.

A useful document is the 4Step iCare Plan. This tool will help start a conversation between you and your healthcare provider and may result in your doctor writing specific physician's orders to ensure that your wishes will be followed by all healthcare providers.

You can learn more about the 4Step iCare Plan and download a copy at [goalsofcare.org/patients-family/4step-icare-plan](http://goalsofcare.org/patients-family/4step-icare-plan).



# Communication

## is a two-way street

Healthcare providers are here to help you but they will bring their own experiences and perspectives to a conversation. The more clearly and directly you can express wishes that follow your values and background, the better your healthcare provider can recommend a course of action that respects and reflects your beliefs and practices. In the same way, it will help if you see your healthcare provider as someone with his or her own unique life experiences and with a background that may be different from your own. In these conversations, remember, we all have the same goal—to help you by providing care that follows your individual wishes.

### Talking to your healthcare providers

Conversations between patients, their families, and healthcare providers can be challenging, and sometimes the challenge is complicated by cultural or ethnic differences that can lead to misunderstanding or seeming insensitivity based on lack of awareness. New Jersey has the most ethnically diverse healthcare provider population and the third most diverse patient population in the US. It is vital for patients, families, and providers to be mindful of ethnic or cultural differences to ensure that treatment decisions genuinely follow the patient's goals of care.



# Document

After you've determined your wishes and discussed them with your family and healthcare professionals it's time to put them in writing.



These documents are known as Advance Directives and there are many types available:

- **Healthcare Proxy** document, you name a person to speak and make medical decisions for you, if you become unable to do so yourself. This is also known as a Durable Power of Attorney.
- **Living Will** is a document used to tell physicians and family about the situations you would want or not want to have life-sustaining treatment in the event you're unable to give informed consent or make your own medical decisions. Living Wills are intended for all adults, regardless of age or health status. In New Jersey, a Living Will is legal if it is either notarized, signed by a lawyer, or simply witnessed by two individuals.

Though Living Wills are binding legal documents, they do have several limitations. A Living Will must be interpreted by the medical team and may require some discussion with your Healthcare Proxy. It's simply not practical for a Living Will to provide specific directions for all of the situations in which life-sustaining treatments, like CPR or surgery, may be required. It's important to know that EMT's can't take direction from these documents. Once emergency personnel have been called, they must do what is necessary to stabilize a person for transfer to a hospital.

Goals of Care Coalition of New Jersey encourages every adult to identify a Healthcare Proxy and consider writing a Living Will so their loved ones and their doctors understand their wishes regarding end-of-life care. Your Healthcare Proxy should thoroughly understand the details of your Living Will and the goals and wishes they reflect.

➤ **POLST** is a set of medical orders and stands for Practitioner Orders for Life Sustaining Treatments. The New Jersey POLST form is a single page medical order that specifically directs medical personnel, including EMT's, on decisions such as:

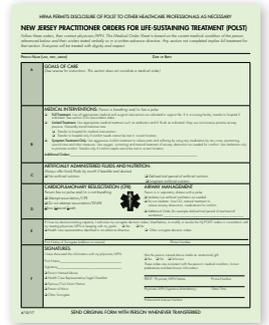
- aggressiveness of care
- returning to the hospital
- artificial nutrition
- and, very importantly, CPR

If a person has a POLST form that says no cardiac resuscitation, EMTs arriving in the home and doctors in the hospital or nursing home may not perform CPR and must allow a natural death.

Unlike a Living Will, which is intended for all healthy adults, a POLST form is reserved only for those adults who are facing serious medical problems or who may be entering their final years of life.

Another important distinction is that a Living Will may only be completed by a patient who has the ability to make their own decisions. A POLST form may be completed by the patient or their Healthcare Proxy if that patient lacks this ability. This means that patients who have dementia or are unable to communicate for any reason, may have a POLST form completed for them.

You can learn more about the POLST form and how to complete one with your healthcare provider at [goalsofcare.org/patients-family/nj-polst](http://goalsofcare.org/patients-family/nj-polst).

The image shows a sample of the New Jersey POLST form. It is a green and white document with the title "NEW JERSEY PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)". The form is divided into several sections: "GOALS OF CARE", "MEDICAL INTERVENTIONS", "PERMANENTLY ADMINISTERED TUBES AND THERAPIES", "PAIN MANAGEMENT", and "SIGNATURES". Each section contains checkboxes and text boxes for medical orders.

POLST forms should be placed in a visible location where medical personnel will know to look for it, such as on the refrigerator or medicine cabinet.

# Working together

To help with these conversations about difficult medical decisions and about end-of-life care, a variety of free resources and videos are available through the Goals of Care Coalition of New Jersey:



4Step iCare Plan form to download and step-by-step videos:  
[goalsofcare.org/patients-family/4step-icare-plan](https://goalsofcare.org/patients-family/4step-icare-plan)



New Jersey POLST form to download in several languages and step-by-step videos:  
[goalsofcare.org/patients-family/nj-polst](https://goalsofcare.org/patients-family/nj-polst)

Resources are also available from other organizations including:

The Conversation Project: [theconversationproject.org](https://theconversationproject.org)

5 Wishes: [fivewishes.org](https://fivewishes.org)

Cake: [joincake.com](https://joincake.com)

Support for this guidebook was provided by the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Foundation.

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Goals of Care Coalition of New Jersey  
Princeton, NJ

## Help us to improve the standard for end-of-life care in New Jersey

Our efforts are made possible through the generosity of our donors. Please consider a tax-deductible donation to help us continue our efforts as advocates for improving communication between patients, families, and healthcare providers, during one of the most important stages of life.

The Goals of Care Coalition of NJ is a 501(c)(3) nonprofit organization working to help patients receive the care they need and no less, and the care they want and no more. We want to ensure that, for every patient entering the final stages of life, all those involved in his or her medical treatment thoroughly understand and follow the patient's wishes, values, and goal of care.

▶ [goalsofcare.org/support-our-efforts](https://goalsofcare.org/support-our-efforts)





# Goals of Care Coalition of New Jersey



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