

### HAVE YOU HAD THE CONVERSATION OF YOUR LIFE?



Have you thought about the medical care you want near the end of your life? Have you shared those thoughts with your loved ones and put them in writing?

If you haven't, you're not alone. Although most New Jerseyans have thought about their end-of-life wishes, less than one third have put those wishes in writing. As a result, too often, people don't receive the care they want. But you can make your wishes known and receive the care you want near the end of your life.

## **ADVANCE CARE PLANNING IS THE ANSWER.**



## WHAT IS ADVANCE CARE PLANNING?

Advance care planning means sharing your preferences for end-of-life care with your loved ones and health care providers and putting them in writing.

Be in control of your medical care with a few simple steps:

#### 1. CONSIDER.

- Consider your own priorities for end-of-life care. If you become unable to make healthcare decisions for yourself, what type of care would you want to receive?
- Consider who you want to make those decisions for you. Who do you trust to be your health care agent?

#### 2. COMMUNICATE.

- Give your health care agent and other loved ones the gift of knowing your priorities and intentions by sharing your thoughts and priorities.
- Communicate your end-of-life care wishes with your caregivers and health care providers.
- 3. CREATE.
  - Put your decisions into a written document. Review your options discussed in this pamphlet.
  - Give a copy to your health care agent, your loved ones, and your health care providers.

## **CONSIDE**R

Consider your options for the care you want to receive when you are nearing the end of your life.

**Understand the difference between PALLIATIVE CARE and HOSPICE CARE.** People often get these two types of care confused.

- Palliative Care can be used at any time during treatment for a serious illness. Palliative care brings together many types of care. It offers physical care but also helps patients with their emotional and spiritual needs. The goal is to achieve the best quality of life available by managing pain and other symptoms.
- Hospice Care is available for someone whose illness, disease, or condition is unlikely to be cured. The goal of hospice care is to maintain or improve the quality of life of patients who are likely to die within six months. The care plan includes help with the physical, emotional and spiritual pain that often accompanies terminal illness. Hospice care includes support for the entire family during the illness and continues with grief support after death.

Talk to your health care provider about how you or your loved ones can get either of these types of care.

#### Consider your priorities for end-of-life care.

It is never too early to start to think about creating an advance directive. You might think that you can't plan for every possibility at the end of your life. You don't have to. One way to start this process is to finish these two sentences.

- I would want to be kept alive as long as I am able to
- Life would no longer be worth living if I had to

Another way to think about this important topic is to use your personal life experiences. Think about people you know who suddenly became ill or injured. What did you learn from that experience that helps you understand your own wishes for the care you would want to receive if this happened to you?

#### Term to Know

Advance directive - a legal document that explains your wishes for the type of medical care you want at the end of your life.

# COMMUNICATE

#### Pick your health care agent.

Your health care agent is the person who can make decisions for you about your medical care if you are not able to make them yourself. This person can be anyone–family or friend–but not your health care provider. The health care agent does not need to know anything about medical care; they only need to know about you and your wishes for care.

- Think about the people in your life who you would trust to follow your wishes.
- Be sure to have a conversation with them to ask if they are willing to take on this responsibility. Talk about your wishes for end-of-life care.
- When you have chosen your health care agent, give them a copy of your written wishes.

Remember, you can change your health care agent at any time.



## CREATE

#### Put Your End-of-life Wishes in Writing.

Fill out an advance directive to help your health care agent, your loved ones, and your health care providers make decisions that reflect your wishes if you can no longer make those decisions yourself.

There are a few ways you can write down your wishes – pick the advance directive that is right for you:

#### • NJ Instruction Directive ("Living Will") and Proxy Directive

The Instruction Directive is a legal document that describes medical treatments you would and would not want. It also includes other decisions, such as your wishes for treating your pain and whether you want to donate your organs. The Proxy Directive (or "Durable Power of Attorney for Health Care") is used to name your health care agent (or "proxy"). Both of these documents must be signed by two witnesses or a notary and will only go into effect if you are no longer able to speak for yourself.

#### • 5 Wishes

Five Wishes is another option. Five Wishes is a legal document written in easy to understand language and many prefer to use this form. It incorporates all of a person's needs (medical, emotional, and spiritual) and helps guide discussions with your loved ones and health care providers. This document requires two witness signatures.

#### • One additional advance directive that you might need someday.

A POLST (Physician Orders for Life-Sustaining Treatment) form is similar to an advance directive because it is based on your wishes for medical treatment, but a POLST is filled out with your health care provider. This form is intended for people with a serious, advanced illness. A POLST serves as instructions to health care providers –almost like a prescription. It is a medical order that travels with you, meaning that hospitals and health care providers outside of New Jersey must follow the directions on this form. This form requires the signature of your healthcare provider.

*REMEMBER:* Share copies of your Advance Directive with your health care agent, your loved ones, and your health care provider. You can create, upload, and share your documents electronically with others at www.mydirectives.com. Your advance directive can be updated or changed at any time.

# COMMON QUESTIONS

#### I'm still young and healthy. Why worry now?

More than anything, advance care planning is a gift to those you love. Making your wishes for end-of-life care known ahead of time saves your loved ones from having to make emotionally hard decisions for your care. They will know your wishes and can focus on spending time with you.

#### This seems overwhelming right now. What should I do?

Begin a conversation with your primary care provider, family, friends, and anyone else you trust. Consider your cultural beliefs, your religious beliefs, and your personal values. Then, start filling out one of the forms described earlier (NJ Instruction Directive, Five Wishes, POLST). Remember, you can always change your mind and write a new plan whenever you want. Just getting your thoughts down is an important start.

#### What if I change my mind about my wishes, or my health care agent?

You can change your mind and create a new document at any time. In fact, it is recommended that you review your document(s) every decade – in your 30s, 40s, etc. – and any time you have a major life event (death of your health care agent, onset of a serious illness, marriage, divorce, etc.). Remember to collect copies of your old document(s) and destroy them. Discuss your new plan with your health care agent and be sure to share copies of your new plan with your health care agent, loved ones, and health care providers.

#### REMEMBER

Share your advance directive with loved ones and your healthcare providers. You can also create or upload your advance directive online and share it electronically with others.

Keep your advance directive in an accessible and secure location.

Revisit your advance directive and end-of-life care conversations every few years, or more often if your health changes.

### THE FORMS YOU CAN USE

Instruction Directive & Proxy Directive www.nj.gov/health/advancedirective/ad/forumsfaqs/

> Five Wishes - Aging with Dignity www.agingwithdignity.org/five-wishes

POLST Form www.state.nj.us/health/advancedirective/polst/

### **USEFUL RESOURCES**

Conversation of Your Life www.njhcqi.org/coyl/

Goals of Care Coalition of NJ www.goalsofcare.org/patients-family/

Death Over Dinner *deathoverdinner.org/* 

Advance Care Planning Decisions, Family Caregiver Alliance bit.ly/2k8Q7SR

Conversation Project, Starter Kit theconversationproject.org/starter-kits/

Toolkit for Health Care Advance Planning *bit.ly/1nSihdi* 

## **GOOD BOOKS TO READ**

Being Mortal, Atul Gawande Can't We Talk About Something More Pleasant? Roz Chast Final Exam, Pauline Chen The Conversation: A Revolutionary Plan for End-Of-Life Care, Angelo Volandes The Best Care Possible, Ira Byock

When Breath Becomes Air, Paul Kalanithi

### **GOOD FILMS TO WATCH**

Amour

Being Mortal: PBS Frontline Documentary Consider the Conversation Life as a House The Bucket List

COYL is a program of the New Jersey Health Care Quality Institute's Mayors Wellness Campaign and brought to you by NJWELL. COYL aims to bring advance care planning conversations to NJ communities.

The New Jersey Health Care Quality Institute aims to improve the safety, quality, and affordability of health care for everyone.

To learn more, visit www.njhcqi.org/COYL.



