



# Advance Care Planning

A GUIDE TO UNDERSTANDING ADVANCE DIRECTIVES



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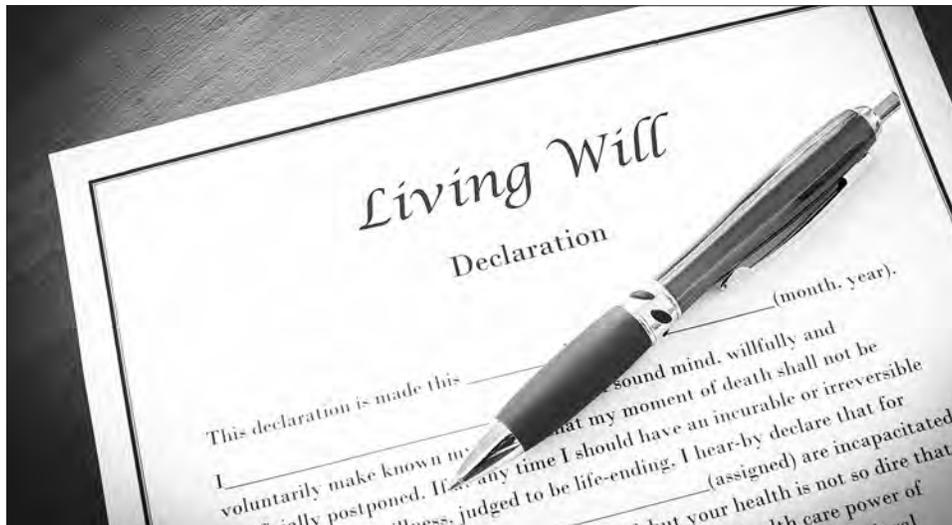
## Introduction

Today there are treatments that can keep patients alive for longer than ever before. A lot of choices may now need to be made — quickly — during a medical crisis. Are there treatments you do not want? Where do you hope to spend your last days? Your loved ones must know what to do if you can't speak for yourself.

Being very sick or injured comes with a lot of challenges. You may feel confused and unsure about the future. You can prepare for these uncertain times. Advance care planning can help. Advance care planning is important for everyone. It can help whether you are healthy, sick but hoping to get better, or very seriously ill.

This booklet is for educational purposes only. It does not give legal advice. The booklet will explain advance directives and guide you through the planning process. An in-depth workbook and tips on how to talk about your wishes and put them in writing are included.

Deciding, discussing, and documenting healthcare wishes is not an easy task for many people. We hope this booklet will help. **Please contact us if you have any questions.**



# What Is Advance Care Planning?

Making healthcare decisions for yourself before you get very ill or injured is called “advance care planning.” You might not think you need to make decisions now if you aren’t sick. Most of us don’t want to think about being very sick, and healthcare choices can be confusing. Many people also find it hard to talk about the end of life.

Advance care planning is important for sick *and* healthy people of all ages. It is never too early to start. Making choices now can help avoid confusion in the future. There are 3 steps to advance care planning:

## **Step 1 — DECIDE**

The workbook starting on page 8 can guide you through this first step. Some questions will help you think about your values. More questions help you decide what kind of care you want if you become seriously ill. This will prepare you to fill out your advance directive.

## **Step 2 — DISCUSS**

Once you’ve thought about your values and wishes, talk about them often. Talk to anyone who might be involved in your care. This may be the most important step in advance care planning. Talking clearly about your wishes can help make it more likely they will be followed.

## **Step 3 — DOCUMENT**

When you’ve talked about your wishes, put them in writing. You can write your wishes in a form called an advance directive. There are also forms you can ask your doctor to fill out.

“Give yourself and others peace of mind by completing your own advance directives. The unexpected can happen to anyone at any age. End-of-life decisions should not be made at the end of life.”

— From Be@Ease.org

## What Is an Advance Directive?

Advance directives are forms that record your healthcare wishes in case you cannot speak for yourself. Standard care in a medical emergency may use life-sustaining treatments such as CPR, feeding tubes, and ventilators (breathing machines) to keep you alive. These treatments help many people. But they may be harmful in some cases. An advance directive can help give you some control over the care you receive.

Advance directives might not be honored if 911 is called. Emergency medical services (EMS) must attempt to save your life *unless* you have a DNR or POLST form (see page 6) posted where they can see it.

What you should know:

- Advance directives take effect when you cannot speak for yourself. You can make choices as long as you can think clearly and act on your own. Some states let you apply advance directives right away.
- You may not need to fill out an advance directive if — no matter what happens — you want all life-sustaining treatments. However, most healthcare experts say it is always best to complete an advance directive so your wishes are clear.
- Your family and care team may need to make decisions for you if you do not have an advance directive. A court may decide what is best for you if your family and care team disagree about your care.
- You can cancel or change your advance directives any time. Let anyone who might be involved with your care know if there are changes. To cancel an advance directive you can destroy the form or fill out a new form. You can also write, sign, and date a letter to your care team to cancel; or ask your healthcare agent (see next page) to write the letter for you.
- You do not need a doctor to sign your advance directive. You can complete an advance directive on your own, though some people choose to work with their estate lawyer or care team.
- The sections you complete still apply if you skip a section.
- Your state might void your advance directive if you are pregnant. Some states have laws that protect the fetus in certain cases. Some states let you choose what you would want if you are pregnant.
- If your child is 18 (in some states, 19) years or older and they want you to be involved in their care, they should complete an advance directive. If not, you might need court approval to speak for them.

Other names for advance directives: living will and durable power of attorney for health care, medical directive, healthcare directive, declaration, healthcare proxy

## Parts of an Advance Directive

Each state's forms vary based on its laws. Most advance directives have 4 main parts. Your state may not have all of them, or the sections may be combined. Some states include other sections or instructions. You can get the forms for free at [www.caringinfo.org/stateADdownload](http://www.caringinfo.org/stateADdownload).

### Durable power of attorney for health care

This legal form names a person as your healthcare agent. **Your healthcare agent will make medical decisions for you if you can't speak for yourself.** They must be 18 (or 19) years or older. Your state may have other rules about who can be your agent.

Naming an agent does not take away your right to make your own choices. You do not have to name an agent. Your next of kin will be asked to speak for you if you do not name someone.

Your agent should be:

- Someone who knows you well, lives close by, and knows your values
- Someone who will carry out your wishes, whether or not they agree with them
- Someone who is not afraid to speak up for you, whom you trust, and who is stable
- One person, instead of a group, to avoid arguments

Your agent may need to:

- See your medical records, keep track of your changing health, talk to the care team, ask questions, and make sure your advance directives are followed
- Decide who will care for you and where care will be given
- Say yes or no to treatments/tests and make choices on things you didn't talk about (with the care team's guidance)
- Work with the person in charge of your money (if that is someone other than your agent) to set up payment for care
- Make choices for your body after death (such as organ donation)

Always ask the person before naming your agent. (See "Tips for Discussing Your Wishes" on page 23.) Some states require the agent to accept by signing the advance directive. You may also want to name a backup agent.

Other names for a healthcare agent: surrogate, proxy, executor, representative, healthcare power of attorney (POA), attorney in fact, advocate

## Living will

This form lets you choose life-sustaining treatments (CPR, feeding tubes, ventilators) if you are dying or are permanently unconscious (such as a coma). Each state's living will is different.

Some let you choose options based on your condition. Some have you agree or disagree with a list of statements. Many have statements about comfort care and pain relief. Most have spaces where you can write other wishes.

Other names for a living will: declaration, healthcare instructions, healthcare choices, treatment preferences

## Organ donation

This form lets you say yes or no to organ donation at death. Your family will be asked about organ donation if you die in a hospital. They will need to decide right away. Most states add this as an extra form after the advance directive. Some combine it with the living will.

Many states let you choose options for donation. Others give your agent the power to choose options for you. A few states also ask about autopsy and burial wishes. There is no cost to you or your family if you donate. Go to **[www.organdonor.gov](http://www.organdonor.gov)** for more information.

Other names for organ donation: anatomical gifts, disposition of remains

## Signature and witness

This is where you sign and date the form to confirm you understand the choices you've made. Most states also need 2 witnesses to sign. This makes the advance directive a legal document. Many states allow a notary to sign instead of 2 witnesses. A few states *require* a notary to sign.

Witnesses must be 18 (or 19) years or older, personally know you, and believe you can think clearly and act on your own. Some states have other rules about who can and cannot be a witness.

Other names for this section: execution, affidavit

## Other Advance Care Planning Forms

Other advance care planning forms include DNR and POLST. These are medical orders if you are seriously ill or near the end of life. These forms must be signed by you or your agent and a doctor. Some states let a nurse practitioner or physician assistant sign them. They are added to your medical record so healthcare staff — including EMS — know your wishes. It's a good idea to complete these forms if you need them, but it's not required.

### DNR (Do Not Attempt Resuscitation) Order

This form tells healthcare staff not to use CPR (cardiopulmonary resuscitation) if your heart/breathing stop. There may come a time when you and your care team decide the risks of CPR (see page 18) are too great. Ask your care team about a DNR order at that time.

Talk to your care team about the pros and cons of CPR if you are 65 years old or over, are frail, depend on others for care, have more than one serious health issue, or have an end-stage illness.

If you get a DNR order, let everyone who may be involved in your care know you have one. Talk to your healthcare agent, family, care team, and others. Post copies of your DNR on your fridge, inside your front door, and wherever they can be easily seen. Consider buying a medical ID card or jewelry.

Other names for a DNR order: DNAR, DNRO, AND (Allow Natural Death), No Code, No CPR

### POLST (Physician Orders for Life-Sustaining Treatment)

This form tells healthcare staff which treatments you want (or don't want) when you are seriously ill. POLST forms do not replace advance directives — these forms work together. An advance directive is filled out ahead of time, in case you get sick. A POLST form is filled out only if you are seriously ill.

Not everyone with an advance directive needs POLST. But if you have POLST, it is wise to also have an advance directive. If you have both, be sure the documents agree with each other. Ask your care team for help, if needed.

Each state has their own version of POLST. Most forms include choices for DNR, level of treatment, and feeding tubes. Some states include other options. Go to **[www.POLST.org](http://www.POLST.org)** for more information.

Other names for POLST: MOLST or COLST (Medical/Clinician Orders for Life-Sustaining Treatment), MOST or POST (Medical/Physician Orders for Scope of Treatment), TOPP or TPOPP (Transportable Physician Orders for Patient Preference), SAPO (State Authorized Portable Orders)

## Advance Care Planning Workbook

The workbook on the next pages is a tool to gather information for your advance directive. **This workbook is not an advance directive. It is not a legal document.** Laws vary by state. Your state's advance directive may ask for more information that is not in this workbook.

**Contact us if you need help.** We can answer questions about the workbook and help you fill out your advance directive.

Workbook tips:

- Some answers may need a lot of thought. Take one section at a time. Take breaks when needed.
- You might have to come back to a question. It is okay to skip questions you do not want to answer.
- Talk to your family, friends, faith community, or care team to help with questions you are not sure about.
- Name a healthcare agent (see pages 4 and 13) if you don't want to take part in your healthcare decisions. Give this workbook to your agent. They may find it helpful.
- **Review this workbook and your advance directives often. You may need to update them as you get older, if you find out you have a serious illness, or if your health gets worse.**

“We call them healthcare decisions,  
but it is really about values.  
The emphasis is not on ‘what’s the matter with you.’  
The question is, ‘what matters to you?’”

— Kate DeBartolo, director of the Conversation Project  
at the Institute of Healthcare Improvement

# Advance Care Planning Workbook

Name: \_\_\_\_\_

Date: \_\_\_\_\_

## Part 1: Think about your values

Your values, beliefs, fears, and hopes can guide your treatment choices.

**What gives your life meaning?** Check all that apply.

**My family.** List their names.

Spouse/partner: \_\_\_\_\_

Children: \_\_\_\_\_

Grandchildren/great-grandchildren: \_\_\_\_\_

\_\_\_\_\_

Siblings: \_\_\_\_\_

Parents: \_\_\_\_\_

Others: \_\_\_\_\_

\_\_\_\_\_

**My friends.** List their names.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**My religion/spiritual beliefs.** What are your spiritual beliefs?

\_\_\_\_\_

**My passions and hobbies.** List them.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**My career.** What is (or was) your career? What part of your job did you enjoy the most?

\_\_\_\_\_

\_\_\_\_\_

**Other:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Advance Care Planning Workbook

**If you didn't list it on page 8, do you practice a religion?**     Yes     No

List your religion, place of worship, and names of trusted spiritual counselors. Or describe your spiritual beliefs if you do not practice a religion.

**Do you have religious beliefs that might affect your healthcare choices? Ask a trusted spiritual counselor if you don't know.**     Yes     No     I don't know

(Examples: I cannot eat animal products; I cannot receive someone else's blood)

**What things or activities do you enjoy?**

(Examples: Your favorite music, books, TV shows, movies, sports, flowers, food, hobbies)

**What do you fear or dislike?**

(Examples: Darkness, certain kinds of music, animals, bugs, foods, smells)

**What does "quality of life" mean to you?**

(Examples: Managing pain, spending time with family, doing things I enjoy, living on my own)

# Advance Care Planning Workbook

## Part 2: Think about your hopes and fears during a serious illness

Your answers will help guide your treatment choices during a serious illness.

**Do you have a serious illness now?**     Yes     No

If "No," it may still help to try to answer some of these questions.

**Is there a coming event that you hope to be a part of?**

(Examples: Wedding, anniversary, birthday, birth of a grandchild)

**Are there things you want to do or projects you want to complete?**

(Examples: Visit a special person, finish a quilt, fix the car)

**What is on your bucket list? What have you always wanted to try?**

(Examples: Travel to a special place, go to a concert, learn how to play an instrument)

**Do you have broken relationships you want to mend?**     Yes     No

If "Yes," name the person(s). What might you do to reach out?

## Advance Care Planning Workbook

### What else do you hope for that might make you feel at peace?

(Examples: Visit from a spiritual counselor, knowing my family will be okay, finding a home for my pet)

### Name friends or loved ones who might be able to help you complete tasks.

\_\_\_\_\_

Name

\_\_\_\_\_

Phone #

\_\_\_\_\_

Name

\_\_\_\_\_

Phone #

\_\_\_\_\_

Name

\_\_\_\_\_

Phone #

### What do you fear about having a serious illness? Check all that apply.

- |  |  |
|--|--|
| <input type="checkbox"/> Being in pain   | <input type="checkbox"/> Not being able to walk or get around by myself                  |
| <input type="checkbox"/> Not being able to breathe on my own                                   | <input type="checkbox"/> Not being able to go to church or practice my spiritual beliefs |
| <input type="checkbox"/> Not being able to talk  | <input type="checkbox"/> Not being able to do things I enjoy                             |
| <input type="checkbox"/> Being on life support   | <input type="checkbox"/> Being a burden to loved ones                                    |
| <input type="checkbox"/> Staying in a hospital   | <input type="checkbox"/> Living in a nursing home  |
| <input type="checkbox"/> Not knowing who I am  | <input type="checkbox"/> Not being able to work  |
| <input type="checkbox"/> Not knowing who loved ones are  | <input type="checkbox"/> Being alone   |
| <input type="checkbox"/> Not being able to take care of my loved ones                          | <input type="checkbox"/> Not being able to live on my own                                |
| <input type="checkbox"/> Not being able to take care of myself (eat, bathe, get dressed, etc.) | <input type="checkbox"/> Dying   |

Other: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Advance Care Planning Workbook

**What are the top 3 most important things for you to get from medical care while you are seriously ill?** Number them 1 (most important) to 3:

- \_\_\_\_\_ Live as long as possible
- \_\_\_\_\_ Increase quality of life (see page 9 for what "quality of life" means to me)
- \_\_\_\_\_ Manage pain and symptoms
- \_\_\_\_\_ Emotional, social, and/or spiritual support
- \_\_\_\_\_ Emotional, social, and/or spiritual support for my loved ones and caregivers
- \_\_\_\_\_ Other: \_\_\_\_\_
- \_\_\_\_\_ Other: \_\_\_\_\_
- \_\_\_\_\_ Other: \_\_\_\_\_

**Doctor(s) you want to be involved in your care, if possible:**

\_\_\_\_\_  
Doctor's Name Phone #

\_\_\_\_\_  
Address

\_\_\_\_\_  
Doctor's Name Phone #

\_\_\_\_\_  
Address

**Hospital(s) you prefer, if possible:**

\_\_\_\_\_  
Hospital Phone #

\_\_\_\_\_  
Address

\_\_\_\_\_  
Hospital Phone #

\_\_\_\_\_  
Address

**If you need ongoing care to meet your wishes, how will you pay for it?** Check all that apply. Ask your care team what your payment options may cover.

- Private health insurance
- Medicare
- Medicaid
- Other: \_\_\_\_\_
- Pay out of pocket
- I don't know

## Advance Care Planning Workbook

### Part 3: Name your healthcare agent

This person will speak for you if you can't speak for yourself.

This section will help you fill out your durable power of attorney for health care (see page 4).

Ask us about your state's rules about who can and cannot be your agent.

- I don't want to name a healthcare agent.** I will let my family, care team, and/or state courts decide what is best for me (skip to the next page).

#### My FIRST choice for healthcare agent:

\_\_\_\_\_  
Name

\_\_\_\_\_  
Phone #

\_\_\_\_\_  
Address

This person is my:

- Parent     Spouse/partner     Child (18/19 years+)     Sibling     Friend  
 Other: \_\_\_\_\_

#### My BACKUP choice for healthcare agent:

\_\_\_\_\_  
Name

\_\_\_\_\_  
Phone #

\_\_\_\_\_  
Address

This person is my:

- Parent     Spouse/partner     Child (18/19 years+)     Sibling     Friend  
 Other: \_\_\_\_\_

**Have you already asked these people to be your agents?**     Yes     No

If "No," see "Tips for Discussing Your Wishes" on page 23.

#### How much flexibility will your agent have in making healthcare decisions for you?

Some people feel strongly about their choices and don't allow flexibility. Others allow flexibility, trusting their agent to make the best choice at the time.

**FULL:** My agent and care team can change my wishes if they think that is best for me.

**SOME:** My agent can change my wishes EXCEPT these: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**NONE:** My agent must follow my wishes EXACTLY, as long as it is reasonably possible.

# Advance Care Planning Workbook

## Part 4: Learn about your illness

Learning about your illness and treatment options can prepare you for what may be ahead. It may still be helpful to fill out some parts of this section even if you are not sick.

### How much do you want to know about your illness and treatment?

Not everyone wants to know all about their illness. Each person has a different comfort level with how much they want to know.

- Nothing:** Skip to Part 5, “Think about treatments during a serious illness” on page 16.
- Some things:** I just want basic information.
- Everything:** I want to know all of the details.

### What do you know about your illness and treatment?

Fill in what you know, based on what your care team has told you. If you don’t know something, do you want to know about it? Check the box that applies. Share this with your care team. They can give you more information if needed.

- **Diagnosis** (the name of your illness):

\_\_\_\_\_

- I don’t know this, but I’d like to know       I don’t want to know this

- **Symptoms** (including ones you don’t have yet):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

- I don’t know this, but I’d like to know       I don’t want to know this

- **Prognosis** (how the illness will likely affect you, now and in the future):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

- I don’t know this, but I’d like to know       I don’t want to know this

- **Life expectancy** (how long you might have left to live): \_\_\_\_\_

- I don’t know this, but I’d like to know       I don’t want to know this

## Advance Care Planning Workbook

- **Treatments suggested by your care team** (see pages 16–19):

I don't know this, but I'd like to know       I don't want to know this

- **Caregiving and support needs** (such as transfer to a hospital, therapy, home care, palliative care, assisted living, nursing home, home health care, hospice care):

**Support you will need now:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

I don't know this, but I'd like to know       I don't want to know this

**Support you may need in the future:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

I don't know this, but I'd like to know       I don't want to know this

**What other questions do you have about your illness or treatment?**

**What else do you NOT want to know?**

# Advance Care Planning Workbook

## Part 5: Think about treatments during a serious illness

Talk to your care team about treatments that might apply to you during your illness.

Common treatments are described in this section. If a treatment might apply to you, check “Yes” if you want it or “No” if you don’t. Spaces to write in other treatments your care team suggests are on the next page.

Add a copy of this section to your advance directive. Ask your care team to add a copy to your medical record or POLST form.

### Treatments during a serious illness or near the end of life may...

#### ...be a good fit if they:

- Relieve pain or suffering
- Increase quality of life
- Are in line with your values
- Improve function

#### ...NOT be a good fit if they:

- Cause pain or other discomfort
- Decrease quality of life
- Are not in line with your values
- Only keep you alive with no other benefit

- **Blood transfusions:** Donated blood is injected into your body. Replaces lost blood. May treat some diseases. Some religions do not support this. Some side effects: back pain, dizziness, fever, shortness of breath.  Yes  No  I don't know
- **Chemotherapy:** Strong drugs are injected into the body to kill cancer cells. May shrink tumors. Some side effects: feeling weak or tired, hair loss, bruising, bleeding, nausea, vomiting, weight loss.  Yes  No  I don't know
- **Dialysis:** A machine filters waste from the blood if your kidneys fail. (Treatment without a machine is possible for fewer patients.) Minor surgery is needed to prepare for treatment. Treatment takes many hours and must be done on a routine, ongoing schedule. Dialysis is not a cure. Some side effects: low blood pressure, nausea, vomiting, a feeling of fullness in the belly.  Yes  No  I don't know
- **Invasive tests:** Such as biopsies or blood tests. Collects body tissues to test for disease. Tests may be painful. Many need surgery. Some risks: bleeding, infection.  Yes  No  I don't know
- **Pacemaker or implanted defibrillator:** A device is placed in your chest or belly with surgery. It keeps your heartbeat steady or shocks your heart if it stops. Some risks: bleeding; bruising; infection; damage to blood vessels, nerves, lungs; pain/burdens at the end of life.  Yes  No  I don't know
- **Radiation therapy:** Beams of intense energy kill cancer cells. May shrink tumors. Some side effects: feeling tired, red/peeling skin, soreness, nausea, vomiting, hair loss.  Yes  No  I don't know

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- **Sedation:** Drugs calm you or put you into a sleep-like state. Relieves extreme pain or unrest. Some side effects after sedation: feeling tired, headache, nausea.  
 Yes     No     I don't know
- **Surgery:** The body is cut open to repair/remove tissues, organs, or bones. May need anesthesia, intubation, or a ventilator. Some side effects: feeling tired or weak, loss of appetite, bruising, swelling, numbness. Risks: pain, bleeding, infection, added burdens near the end of life.     Yes     No     I don't know
- **X-rays, PET/CT/CAT scans, MRIs:** Images are taken of the inside of the body. Can show how an illness has progressed. Often painless. Will expose you to low beams of radiation or magnetic/radio waves. Some side effects: nausea, headache, dizziness.  
 Yes     No     I don't know

**Write other treatments your care team suggests below.** Ask about the possible pros and cons of each. Then choose whether or not you want the treatment.

- **Treatment:** \_\_\_\_\_  
**Pros:** \_\_\_\_\_  
\_\_\_\_\_  
**Cons:** \_\_\_\_\_  
\_\_\_\_\_  
 Yes     No     I don't know
- **Treatment:** \_\_\_\_\_  
**Pros:** \_\_\_\_\_  
\_\_\_\_\_  
**Cons:** \_\_\_\_\_  
\_\_\_\_\_  
 Yes     No     I don't know
- **Treatment:** \_\_\_\_\_  
**Pros:** \_\_\_\_\_  
\_\_\_\_\_  
**Cons:** \_\_\_\_\_  
\_\_\_\_\_  
 Yes     No     I don't know

# Advance Care Planning Workbook

## Part 6: Think about treatments near the end of life

This will help your care team update your medical record or fill out a POLST form (page 6) if you are seriously ill or near the end of life. This section should be filled out after an in-depth talk with the care team about your values, condition, and goals.

**CPR (cardiopulmonary resuscitation):** Used if your breathing or heart stops. CPR may combine chest compressions (pushing down hard on the chest), rescue breaths, intubation, electric shocks to the heart, and medicine. Risks: being taken to a hospital or ICU; being hooked up to machines; damage to the ribs, lungs, brain, or other organs. Check one:

- Yes, I want CPR if I am seriously ill or near the end of life.**
- No, I do not want CPR if I am seriously ill or near the end of life. (Ask your care team to complete a DNR order or a POLST form, see page 6.)**

**ANH (artificial nutrition and hydration):** Feeding tubes give you liquid food if you cannot swallow or feed yourself. Tubes are pushed into the stomach through the nose, mouth, or belly, sometimes with surgery. This can keep you alive but it will not cure your illness. Risks of feeding tubes: aspiration (getting saliva, vomit, etc., in the lungs), lung infection, other infections, nausea, vomiting, ulcers.

IVs give you fluids and medicine. They are placed with needles. IV fluids near the end of life may cause added pain or discomfort. Check one:

- Yes, I want ANH if I am seriously ill or near the end of life.**
- No, I don't want ANH if I am seriously ill or near the end of life.**
- I want a time-limited trial of ANH, if approved by my care team**

Your care team might approve a time-limited trial of treatments like ANH. You can try the treatment for a set amount of time. You can keep doing it if it helps. Treatment is stopped if it does not help or causes harm. It might be harder to stop a treatment than to not start it at all.

“What really makes these decisions ‘hard choices’ has little to do with the medical, legal, ethical, or moral aspects of the decision process. The real struggles are emotional and spiritual....These are decisions of the heart, not just the head.”

— Hank Dunn, from *Hard Choices for Loving People*

# Advance Care Planning Workbook

## **MEDICAL INTERVENTIONS:**

The kind of treatment you want if you cannot communicate and are seriously ill or near the end of life, are breathing, and have a pulse. Check one:

**FULL TREATMENT.** Prolong life with all suggested treatments. May include:

- Intubation — A tube is inserted into your airway or stomach through the nose, mouth, throat, or belly. Some have to be placed with surgery.
- Ventilator — A breathing machine keeps you alive if you cannot breathe on your own. Air is pushed into the lungs through a tube. You won't be able to talk.
- Transfer to the hospital
- Transfer to ICU — Intensive care unit. You will often be hooked up to many tubes and machines. Staff watches you closely. Visitors are limited.
- Treatments listed below, as needed

**LIMITED TREATMENT.** Basic medical care. Avoids intubation, ventilators, ICU, and added burdens. May include:

- Antibiotics — Medicine to treat infections. Some side effects: upset stomach, diarrhea.
- IVs — Gives you fluids and medicine. A small tube is inserted into a vein with a needle.
- Heart monitors — Keeps track of heart rate and breathing. A non-painful device is used.
- Transfer to the hospital only if needed
- Referral to palliative care — A team-approach to care. Treats pain and symptoms. Gives emotional and spiritual support to the patient and family.
- Treatments listed below, as needed

**COMFORT MEASURES ONLY.** Symptom management. Focus on comfort and easing suffering. Avoids transfers to the hospital or ICU. Avoids life-sustaining treatments (CPR, intubation, ventilators). May include:

- Medication for pain management — May include opioids such as morphine. Given by mouth, suppository, IV, or injection. Common side effects (which are treated): constipation, itching.
- Antibiotics and other medicine to help ease symptoms
- Wound care
- Oxygen for comfort
- Suction — Mucus, saliva, blood, vomit are vacuumed out of the airway. Helps you breathe. May prevent choking.
- Transfer to the hospital only if symptoms cannot be managed where you are
- Referral to palliative care or hospice care — Hospice care is multi-level care for dying patients with 6 months or less to live (see the next page).

# Advance Care Planning Workbook

## Part 7: Think about care you want at the end of life

This section will help you fill out your Living Will (see page 5).

**Do you want your life prolonged for as long as it is reasonably possible if you are dying or permanently unconscious (in a coma or persistent vegetative state)?**

- Yes     No     I don't know

**Do NOT prolong my life if:** Check all that apply.

- I'm dying (have a terminal illness)                       I have severe dementia  
 I am permanently unconscious                               I have severe brain damage  
 I've been on life support for \_\_\_\_\_ (days / weeks / months) with no improvement  
 Other: \_\_\_\_\_

**Do you want a feeding tube/IV fluids if you can't eat or drink on your own at the end of life?** (See ANH on page 18.)     Yes     No     I don't know

**Do you want a feeding tube/IV fluids if you are permanently unconscious?** (See ANH on page 18.)     Yes     No     I don't know

**Where do you hope to spend your last days?** Check all that apply.

- Home     Hospital     Nursing home     Assisted living  
 It doesn't matter to me     Other: \_\_\_\_\_

**Where do you NOT want to spend your last days, if possible?** Check all that apply.

- Home     Hospital     Nursing home     Assisted living  
 It doesn't matter to me     Other: \_\_\_\_\_

**Do you want hospice care if you have a terminal illness?** Hospice care treats a dying patient's unique physical, emotional, social, and spiritual needs. Support is given to family and caregivers.     Yes     No     I don't know

**If your state has a right to die law, is this an option you might want?**

- Yes     No     I don't know

Also known as "medical aid in dying" or "physician-assisted death with dignity." Laws allow some dying patients to get medicine to end their lives. Most states do not have a right to die law. **NOTE: If your state has a right to die law and you checked "Yes," talk to your doctor.** A doctor has the right to refuse this request. You may need to find another doctor who will agree to follow your wishes.

## Advance Care Planning Workbook

**Other instructions for my health care near the end of life:**

“I have a healthcare directive not because I have a serious illness, but because I have a family.”

— Ira Byock, MD, FAAHPM, author of *Dying Well, The Best Care Possible,* and *The Four Things That Matter Most*

# Advance Care Planning Workbook

## Part 8: Choose donation and other options after death

This part lists options for your body after death. Your state may not offer all of these options.

### Do you wish to donate organs, tissues, or body parts after you die?

- Yes     No

If you chose "Yes":

- All organs, tissues, or parts that are needed and can be used

- Only these organs or parts: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Do you wish to donate your whole body for research after you die?

- Yes     No

### Do you want an autopsy (surgery after death to find out the cause of death)?

- Yes     No     Only if it is needed by law

### After death, I want my body to be:

- Buried     Cremated     Other: \_\_\_\_\_

### This person should be in charge of my funeral plans:

- My agent (see page 13)     Other:

\_\_\_\_\_  
Name

\_\_\_\_\_  
Phone #

### Funeral home I prefer:

### Other instructions to follow after my death:

## Tips for Discussing Your Wishes

- **Start talking about your wishes now.** The best time to talk is before a health crisis. Talk to your healthcare agent, family, care team, and others who may be involved in your care. Set aside plenty of time. Pick a quiet, private place to talk.
- **If you and your family disagree on what is best for you, talk about your wishes often.** Make it clear what your wishes are and insist your wishes are followed. Spiritual beliefs, family culture, relationships, and personalities can all play a role in how a person feels about healthcare wishes.
- Fill out the advance care planning workbook (page 8) first. This can help guide your talks. Things you can say to start:
  - “I’ve been thinking about the future. I think it’s a good idea to talk about my healthcare choices. Can we talk about this?”
  - “My care team suggested I talk to loved ones about my healthcare choices. I’d like you to know more. Do you have time to talk?”
  - “I’ve filled out an advance care planning workbook. Now I need to share my wishes with others. Will you review this with me?”
- It may be uncomfortable to discuss at first. You don’t need to have the conversation all at once. Some people may get upset or need time to think. Stop and try again later. Having a few short talks over time might make it easier.
- Use these tips when asking someone to be your healthcare agent. Go over this booklet with the person. This will help them know what to expect.

## Tips for Documenting Your Wishes

- Fill out advance directives for all states where you spend a lot of time.
- Scan and/or photocopy your advance directives and DNR/POLST forms.
  - Give a copy to your care team to add to your medical record.
  - Send copies to your healthcare agent and family.
  - Post copies at home where they can be easily seen (put DNR/POLST forms on top).
  - Keep copies in your car, purse, or wallet.
- Use secure electronic methods to record your wishes. This may make it easier to find your wishes when they are needed.
  - Add notes about your wishes on your phone. Some phones have a “Medical ID.” It can be set so that others can view it even if the phone is locked.
  - Apps and online registries can help you share your wishes. Some let you record videos. Videos are a good way to make your wishes even more clear.
- **Review your advance directives often. Update them if your health status changes or as needed.** Update them if you are no longer close with your healthcare agent. Give new copies to your care team, current healthcare agent, and family.

## More Resources

Links mentioned in the booklet are listed below. Other helpful links are also listed. These include more tools to help you complete your advance directives.

- Be@Ease, Planning for the Unexpected, [www.BeAtEase.org](http://www.BeAtEase.org)
- Free advance directive download by state, [www.caringinfo.org/stateADdownload](http://www.caringinfo.org/stateADdownload)
- Information on Organ Donation, [www.organdonor.gov](http://www.organdonor.gov)
- POLST (Physician Orders for Life-Sustaining Treatment), [www.POLST.org](http://www.POLST.org)
- The Conversation Project, [www.theconversationproject.org](http://www.theconversationproject.org)
- *Hard Choices for Loving People*, by Hank Dunn, MDiv, [www.hankdunn.com](http://www.hankdunn.com)
- Ira Byock, MD, FAAHPM, [www.irabyock.org](http://www.irabyock.org)
- National Hospice and Palliative Care Organization, [www.nhpco.org/patients-and-caregivers/](http://www.nhpco.org/patients-and-caregivers/)
- AARP, American Association of Retired Persons, [www.aarp.org](http://www.aarp.org)
- Institute on Healthcare Directives, [www.institutehcd.com](http://www.institutehcd.com)
- PREPARE program, [www.prepareforyourcare.org](http://www.prepareforyourcare.org)
- Five Wishes, [www.agingwithdignity.org](http://www.agingwithdignity.org)
- My Directives, [www.mydirectives.com](http://www.mydirectives.com)
- My Life & Wishes, [www.mylifeandwishes.com](http://www.mylifeandwishes.com)
- U.S. Living Will Registry, [www.usacpr.net](http://www.usacpr.net)

**The time you spend planning now is a gift for your loved ones in the future.  
Start planning and talking about your wishes today.  
Contact us for support. We are here for you.**



Questions and Notes:

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