

Advance Care Planning Workbook

A step-by-step guide for putting your medical wishes in writing.



munsonhealthcare.org/acp

We never know what may happen on any given day, and life can bring unexpected twists and turns. That's why making some important life plans now is important – and can alleviate unnecessary stress for our loved ones in the future. The very best time to talk about the type of medical care you may or may not want is when you don't need it.

Advance Care Planning

Advance Care Planning involves exploring the types of medical decisions that may need to be made as we go through life — at present time, in the future, and at the end of life. Goals are likely to change over time, so these conversations should happen any time life circumstances change. This process allows your voice to be heard, even if you cannot speak. Your loved ones and your health care team can't honor your wishes if they don't know what they are. We encourage everyone 18 and older to complete an advance directive or medical durable power of attorney.

Two key components of Advance Care Planning:

- 1. Choosing a person who will carry out your wishes should you become so sick that you are unable to share this information yourself.
- 2. Using an advance care planning document to put your wishes in writing. These documents are referred to as an advance directive or a medical durable power of attorney.

FAQs

What is an Advance Directive?

Examples of advance medical directives include durable power of attorney for health care and the FIVE Wishes booklet. An advance directive is a legally binding document that allows you to designate who will advocate on your behalf and share your medical choices if you are ever unable to speak for yourself. Your designated spokesperson is referred to as your "patient advocate." Your patient advocate is **only** authorized to make medical treatment decisions on your behalf if/when you are unable to speak for yourself. Your patient advocate is required to sign the acceptance form stating their willingness to honor **your** wishes, even if he/she does not entirely agree with them.

Why do I need an Advance Directive?

Unfortunately, many people think they don't need an advance directive because they are healthy and well. However, life happens. Things change — sometimes in the blink of an eye. We value your right to make your own decisions. We encourage everyone over the age of 18 who is legally competent (i.e. does not have a court-appointed guardian for medical decisions), and is of sound mind, to put their wishes in writing and to update those wishes as things change throughout a lifetime. It is impossible to predict when you may become seriously ill or involved in an accident, possibly leaving you unable to speak for yourself. Not having an advance directive in place puts a burden on your loved ones, or the court system, to make decisions on your behalf. It's better to plan 10 years early, than one day too late.

Who should I pick as a patient advocate?

It's important to pick the right person(s) to be your patient advocate(s) because this role carries significant responsibilities. You may feel your spouse or adult children would be the best choice. Others may decide this responsibility is too emotional or difficult for close family members. Please be sure that your patient advocate(s):

- is 18 years of age or older, and is someone you trust to make important life decisions on your behalf
- knows you well and understands what is important to you
- is willing to follow your instructions, even if this results in allowing you to die
- will be strong enough to act on your wishes, separate from his/her own feelings
- can handle conflicting opinions that may arise with family members, friends, and medical clinicians regarding your choices

Where do I begin?

Step 1:

Acknowledge that advance care planning is an ongoing process. Considerations:

- Begin by thinking about your own beliefs, values, and preferences.
- Think about the medical care you would or would not want when you reach the end of your life.
- Recognize this process takes time and should include many conversations during your lifetime.
- Acknowledge that you may face a time in your life when you have adapted to change due to an illness or injury; developing a "new normal" is very common and should prompt more conversations about what is important for you to live a fulfilling and meaningful life.

Step 2:

Consider the conversation

If you are feeling unsure about how or what to say to loved ones, you are not alone. Because we never know what can happen on any given day or how an illness may progress, many people avoid talking about it all together. Unfortunately, this results in significant distress to a family when a crisis occurs or when someone becomes more ill. When a person no longer is able to talk about their goals for living a meaningful life, or too sick to make decisions for themselves, family members are asked to make difficult decisions they oftentimes aren't prepared to make. Things to keep in mind:

- It's important to give your loved ones the gift of knowing your wishes and asking for this gift in return.
- You will not be able to figure out every possible scenario that may occur during your lifetime, so start by talking about what brings quality to your life.
- Using terms such as "pull the plug" or "being a vegetable" often are not helpful; it is better to describe how your life would look at such a time.
- Some people use terms like "quality of life" or "suffering," but this, too, is difficult to assess without knowing how you define these.

Step 3:

Think about your wishes

What are your thoughts about Life-Support? Did you know that what most people would describe as "life-support" doesn't start out that way? Many times it starts out as a treatment option to an illness or injury that might have occurred and one can recover from. For example, if you have pneumonia and were having difficulty breathing, a breathing machine may help you rest while the infection heals and could be a short-term treatment option. Additional questions to consider:

- 1. What are you willing to try if it will help you get better? How long would you be willing to try? How would you describe getting better?
- 2. What if you were already very sick and have lost significant quality of life would you still want to try? What if it wasn't helping the way we hoped it would?
- 3. Some people have said there are certain living conditions they would describe as being worse than death. Are there conditions you would describe in the same manner?
- 4. Would you prefer to be allowed to die rather than be dependent on machines to live?

What are your thoughts about CPR and Do-Not-Resuscitate (DNR)? There is significant confusion around CPR and DNR orders. CPR is a great medical procedure for saving the life of someone who has sudden cardiac arrest. Many assume CPR also is great for saving the life of someone who is elderly, chronically sick, or dying. Unfortunately, the outcomes are significantly worse for these individuals. This is more complicated in a hospital setting where the use of advanced medical technology can interfere with the natural dying process for someone who is chronically ill, very sick, or in the dying process.

Differentiating CPR and DNR:

CPR stands for cardiopulmonary resuscitation and is an emergency medical process involving a number of emergent medical techniques that try to replicate the function of a person's heart and lungs which are no longer working.

A DNR is a binding medical order indicating CPR should not be started if a person has no pulse and is not breathing.

Many people fear that if they say they want a DNR, that they will not be offered any medical care. <u>This is</u> <u>not true</u>. People who do not want CPR performed should have a DNR order completed by their physician, nurse practitioner, or physician assistant. Stating you do not want CPR in an advance directive is a preference, not a DNR order.

For more information about CPR or DNR orders, please talk with your physician, your health care team, or contact the advance care planning department at **231-935-6176**.

The following worksheets may be helpful when considering these conversations; the *Meaningful Living Worksheet*, the *Treatment Wishes Worksheet*, and the *End of Life Planning Worksheet*. These tools may help you identify when an illness or changes in your quality of life would affect the decisions you make.

Meaningful Living Worksheet

Name:	DOB: Today's date:
	,
How you describe living well depends on you	r own values, goals, and experiences. If you were faced with a
now you describe living well depends on you	i Own values, goals, and expenences. If you were faced with a

serious illness that changed your quality of life, how would you describe the situations below?

If Imy life would be	Worth Living	Barely Worth Living	Not Worth Living	Unsure
Could not think clearly and am confused most of the time				
Could no longer make my own decisions most of the time				
Had discomforts such as nausea, diarrhea, or shortness of breath most of the time				
Had severe pain or discomfort most of the time				
Could no longer contribute to my family's well-being				
Could no longer go to social activities such as church, shopping, or visiting others				
Could not communicate in a way that people could understand me				
Were confined to a wheelchair most of the day				
Could no longer be spoon-fed safely and needed to be fed via a tube				
No longer recognize my family members or loved ones				
Were a severe financial burden on my family				
Could not feed myself and needed to have others feed me most of the time				
Were no longer able to talk and be understood by others				
Needed someone to bathe me and/or get me dressed each day				
Needed someone to care for me 24 hours a day				
Lost my mobility and could no longer get out of bed on my own, but I could think clearly				
Were paralyzed, but could think clearly most of the time				
Needed to rely on a breathing machine for breathing to live				
Needed to rely on a feeding tube for nutrition to live				

Treatment Wishes Worksheet

Please check the box indicating your treatment wishes for each situation.

Agree	Disagree	Unsure
	our loved one	s about:

End-of-Life Planning

The fear of the unknown

Much of the worry people have regarding death is the fear of the unknown. First, it's important to acknowledge that dying is a process and not a moment. This can help you prepare and plan for what to expect when you or a loved one is dying. Building a trusting relationship with your physician and your family will help you identify how a life-limiting illness or incurable disease will progress. The gift of time will give you the opportunity to take control of how you live while dying.

How much time do I have left?

Since each person approaches death in their own way, let's consider the timeline. Many times, we aren't sure when someone will die, but the healthcare team often can predict a timeframe from hours to days, days to weeks, or weeks to months. There is no perfect prediction and medicine never stands in the way of a miracle or God's work.

Transitioning from living to dying

Accept that dying is normal and should be looked at differently than living. The shift from living to dying can include many facets. Some people may experience a period of withdrawal and not feel like having visitors, and others may experience long periods of sleep or be confused at times.

There will come a time when food is no longer a priority. This is because we eat to live, and when someone is dying, the body no longer needs this source of energy. This is often the most difficult for family members to accept. Know that forcing nutrition via tubes causes significant discomfort and suffering to a person who is in the dying process.

Skin color and breathing patterns also will change when someone is dying. There may be some shortness of breath, anxiety, or restlessness, but this can be comfortably managed with appropriate medications. Increasing pain may require more pain medication than the person typically had required to manage symptoms prior to entering the dying process. Hospice care can help someone have good quality of life during their dying process and can even extend one's life. If you have more questions about hospice care, please ask your physician or visit **nhpco.org**.

Consider the following questions

What are your fears, if any, regarding end-of life?

If I had severe pain, I want to receive enough pain medications to control my pain, even if it makes me drowsy or puts me to sleep much of the time. **Please circle your answer: Yes**No

When I am dying, I would prefer to be at (home, hospital, etc.)spiritual leader, etc.)	with my (family,
If I could plan it today, the last days or weeks of my life would look like this:	

If I were very ill and not likely to recover, I would want to have palliative or hospice care made available to assure I was comforted and that my symptoms were managed. **Please circle your answer: Yes**No

For more information about palliative and hospice care, please visit the National Hospice and Palliative Care Organization at **nhpco.org**

Now that you have considered what is important to you and what you'd like to talk with your loved ones about, it's time for the most important part: starting the conversation.

Step 4:

Talking with your loved ones

Include your loved ones in the conversations along with your patient advocate(s) and encourage them to do this for themselves as well. After all, this affects the entire family.

Don't be alarmed if your loved ones might not be ready to talk with you about this. We encourage you to keep trying, and keep in mind that their reluctance to talk about this with you could be an indicator that they may not be the most appropriate patient advocate for you.

Having brief conversations is a good way to start and you can build on these each time. Allow yourself to answer any questions your loved one may have and to seek clarification about your family's understanding of what you may be saying.

Using the worksheets is a great way to get the conversations started and to break the ice with those at the table.

Step 5:

Putting your wishes in writing and completing your advance medical directive

With many options for advance directives, choose the one that speaks to you best. The state of Michigan requires the following for any advance directive or durable power of attorney for healthcare: your signature in presence of two witnesses; and your patient advocate's signature of acceptance stating they understand and agree to carry out your wishes.

You can request a copy of the Advance Medical Directive and Treatment Preferences form at most nursing stations, in the main lobbies of Munson Healthcare hospitals, or find it online at:

munsonhealthcare.org/acp-resources

Step 6:

Storing your completed advance directive

You keep the original!

Get a copy to:

- Your physician(s)
- Your patient's advocate(s)
- The local hospital
 - Mail: Munson Healthcare Health Information Management Department

1105 6th street

Traverse City, MI 49684

- Email: MMC-HIM-AMD@mch.net
- Fax: 231-935-6615 or 231-935-6149

Step 7:

Keep the conversation going and update your advance medical directive as needed

You can make changes to your advance directive at any time. We recommend you update your document every few years, or follow the 5D rule:

- every new DECADE of your life
- after the DFATH of a loved one
- after a DIVORCE
- after a significant DIAGNOSIS
- after any DECLINE in function

For more information, contact Advance Care Planning at **231-935-6176** or email **advancecareplanning@mhc.net**.

For additional forms or assistance with questions about your wishes and completing this form, please contact one of the following:

Munson Medical Center Advance Care Planning Department

1105 Sixth St.

Traverse City, MI 49684

231-935-6176 or 800-847-8474 advancecareplanning@mhc.net

Munson Healthcare Grayling Community Health Center

1250 E. Michigan Ave. Grayling, MI 49738

989-348-0550

Munson Healthcare Prudenville Community Health Center Social Work

2585 W. Houghton Lake Dr. Prudenville, MI 48651

989-366-2900

Kalkaska Memorial Health Center Patient Liaison/Representative

419 S. Coral St. Kalkaska, MI 49646 **231-258-7532**

Munson Healthcare Otsego Memorial Hospital

825 N. Center Ave. Gaylord, MI 49735 **800-322-3664**

Paul Oliver Memorial Hospital Patient Liaison/Representative

224 Park Ave. Frankfort, Michigan 49635

231-352-2265

Munson Healthcare Cadillac Hospital Social Work or Spiritual Care Department

400 Hobart St. Cadillac, MI 49601 **231-876-7200**

Munson Healthcare Grayling Hospital Social Work

1100 Michigan Ave. Grayling, MI 49738 989-348-0870

Munson Healthcare Roscommon Community Health Center

234 Lake St. Roscommon, MI 48653 **989-275-1200**

Munson Healthcare Charlevoix Hospital

14700 Lake Shore Dr. Charlevoix, MI 49720 **231-547-4024**

Munson Healthcare Manistee Hospital

1465 East Parkdale Ave. Manistee, MI 49660 **231-398-1000**

