

# Advance Care Planning

Advance care planning (ACP) is a process that involves thinking and talking about complex and sensitive issues regarding your future healthcare. The education and questions that follow will help you and those closest to you understand what you need to do.

## Choosing a healthcare agent

You have many rights when you receive healthcare, including the right to:

- Be told about medical choices and their risks and benefits
- Accept or refuse these choices
- Have your choices honored

You also have the right to choose someone who can make medical decisions for you and be your voice if you can't speak for yourself. This person is called a healthcare agent.

## Things to think about when choosing a healthcare agent

The person you choose to be your healthcare agent must be willing to:

- Take on this role and responsibility.
- Talk with you about the healthcare you want or don't want if you have a serious injury or illness.

They must also be able to:

- Follow through on your healthcare decisions even if they do not agree with your choices.
- Make these medical decisions in difficult and often stressful situations.

If the person you have chosen cannot answer "yes" to all of these responsibilities, you may want to choose someone else to be your healthcare agent.



## Preparing your healthcare agent

Invite your healthcare agent to go with you to your healthcare appointments. This will help them get to know your provider. It will also allow them to ask questions so they understand your health conditions or concerns.

Your healthcare agent needs to understand your wishes for future medical care and what matters most to you. Talk with them about the kind of care you would want or not want.

The following sections will help you walk through some questions that can help shape your advance healthcare plan.

## Looking back

Who we are, what we believe, and what we value are all shaped by our life experiences. Religion, family traditions, jobs, and friendships affect us deeply. Answer the following questions:

- Has anything happened in your past that shaped your feelings about medical treatment?
- Think about an experience in which a family member or friend was faced with a decision about medical care near the end of life.
  - What was positive about that experience?
  - What do you wish would have been done differently?

## Here and now

Understanding what your health status is now is important when making decisions about future medical decisions.

- Do you have any significant health problems?
- What kinds of things bring you joy? If a health problem kept you from doing them any longer, would your life's meaning change?
- What short- or long-term goals do you have? How might medical treatment help or hinder your efforts to attain those goals? What are the risks?

## Planning for tomorrow

Thinking about the future can sometimes seem impossible. Here are some questions to ask yourself:

- What significant health problems do you fear may affect you in the future?
- How do you feel about the possibility of having to go to a nursing home?
- How would decisions be made if you could not make them?

Providing instructions for future healthcare decisions may seem like an impossible task. How can you plan for all the possibilities? You can't, and you don't have to. However, you DO need to plan for situations in which you:

- Become unexpectedly incapable of making your own decisions.
- Will clearly have little or no recovery.
- Have an injury or loss of function that is significant.

These situations might be caused by an injury to the brain from an accident, stroke, or a slowly progressive disease like Alzheimer's.

To plan for this type of situation, many people say, "If I'm going to be a vegetable, let me go," or "No heroics," or "Don't keep me alive on machines." While these remarks are a beginning, they are not clear enough to guide decision making.

**You need to completely describe the circumstances when the decision would change from attempting to prolong life to allowing a natural death.** In some situations, certain treatments may not make sense because they will not help, but other treatments will be of important benefit.

## Examples of treatment and care options can include:

- Oxygen support.
- Antibiotics.
- Short term and long-term artificial nutrition (feeding tube).
- Intubation (breathing tube attached to a ventilator machine — requires treatment in the ICU).
- Pain management.
- Surgery.
- Chemotherapy or radiation therapy.
- Blood product transfusion.
- Rehabilitation services (for example, physical therapy, occupational therapy, speech therapy, short-term care in a nursing home).

## Consider these questions:

- When would it make sense to continue certain treatments to prolong life and seek recovery?
- When would it make sense to stop or withhold treatments, and accept death when it comes?
- Under any circumstance, what kind of comfort care would you want?
  - How would you want medications to be used to provide comfort?
  - What type of spiritual care would you want?
  - Are there certain things you would want around you that provide joy and comfort?

## Time trials

Something to consider when deciding what care you want, is if you would be willing to try certain treatment options for a short time to see if your health improves and if it aligns with what matters most to you. Some examples of treatment options to consider include intubation, ICU care, chemotherapy, or rehabilitation.

Example of how a trail trial period can be worded in your advance directive document are:

“I am willing to try artificial nutrition for 4 weeks. If after the 4 weeks my doctor does not feel I have made any progress and will not in the near future, then I choose to stop artificial nutrition and allow for a natural death.”

“I am willing to try intubation for 2 weeks. If after the trail period I have not improved, I choose to have my healthcare agent stop my intubation and allow for a natural death.”

## Making these choices requires:

- Understanding your condition and situation
- Weighing the benefits and burdens of treatment from your perspective
- Understanding of the treatments and expected outcomes, compared to your identified wishes and preferences
- Discussing your choices with those closest to you
- Writing your choices down in an advance directive, being specific and not using unclear terms. Some examples of unclear terms include “If I’m going to be a vegetable, let me go,” or “No heroics,” or “Don’t keep me alive on machines.”

