

Planning for the future

Having an Advance Care Plan for health care is important. Like all planning it involves thinking ahead. Advance care planning involves thinking about what you would do if you became so ill that you could no longer communicate with your loved ones or health care providers. You may be in good health right now, or you may have a chronic or serious health issue. But all of us need to think about what we would want if we were suddenly injured or suffered a tragic illness and were unable to hear or speak with others. **WHO** would talk with the doctor and nurses to make decisions for you? **WHAT** would they decide?

The Call No Parent Wants

When Andrea was involved in a serious car accident on a trip home from college, her mom rushed to the hospital where she was surprised to learn that she had a limited right to know about her daughter's condition or to provide direction in her care. In the eyes of the law, her 18 year old daughter was now an adult. Sadly, even though Andrea's father had been unavailable in the years since their divorce, now he was insisting to be involved with decision making.

What is advance care planning?

Advance care planning is a process for making decisions now for future health care you may need when you are no longer able to convey your preferences. It involves having conversations with your family and your health care providers. Ideally you do this planning while you are healthy, have mental capacity and are not stressed by bad news about your health. Advance care planning encourages you to define your values and preferences for treatment if cure is no longer possible or you are in an irreversible coma—situations where you can only be kept alive with a variety of tubes or may totally dependent upon caregivers in a skilled nursing facility.

Think About the Unthinkable

Things happen—college students become gravely ill or have serious accidents every day—so it's important to have a plan in place. Because of the Health Insurance Portability and Accountability Act (HIPAA), once a child turns 18, a parent has no more right to obtain medical information on their legal-age son or daughter than they would to obtain information about a stranger even if they carry the health insurance and pay the bills. A medical provider may choose to disclose information to the parent if in professional judgment it serves the best interest of the patient but providers often maintain patient privacy, especially if they've never met the family.

It's best to choose an agent in advance and to tell them about health care wishes; if you do not choose someone in advance, the law will assign a decision maker. Having a conversation is imperative because it's impossible to put every single decision your agent might face in writing. The conversation can enhance their confidence and comfort should the need arise to make health care decisions for you. Young adults with chronic health conditions should ALWAYS designate an agent.

How do I prepare a directive?

1. Define your goal for seeking medical treatment. Is quality of life most important or quantity of days? Are you seeking comfort or cure?
2. Identify who will speak for you when you cannot speak for yourself. Make sure this person agrees to be your agent and understands your preferences.
3. Prepare a healthcare directive. Put your preferences in writing, get the document notarized, give a copy to your agent, and put a copy on your medical record.

Do I need a lawyer?

No. You do not have to hire a lawyer to draft a healthcare directive. The only requirement is that you be an adult of 18 years of age or older and have mental capacity when you write the directive. Most states require that you authenticate your signature with a notary or two witnesses. This document only takes effect when you cannot speak for yourself.

How much does it cost?

There is no cost associated with writing your own healthcare directive. Forms are free and are available at clinics, hospitals, and skilled nursing facilities. Forms for all states are available on-line too.

Important Documents

Completing healthcare directive and general durable power of attorney forms in advance will facilitate involvement of the parent or other trusted adult in an emergency. These are essentially permission slips that enable a designated person to help. Young people who want parents to be involved in a medical emergency but fear disclosure of sensitive information can stipulate within their directive not to disclose information about sex, drugs, mental health, or details they want to keep private. A general durable power of attorney allows a parent to access bank accounts, pay bills, and take care of business if necessary. The student privacy can be protected by stipulating these are "springing" powers which spring into action only if the student becomes incapacitated. The agent should be given a copy of these documents and the student can scan or save a copy of these documents on a smart phone so they are readily accessible. The American Bar Association even endorses digital directives such as *My Directive* or *My Health Care Wishes* apps because this information is easily accessible to view, text, email, or fax no matter where you are.

What if I need help?

Providers and nurses in the clinic, hospital, or skilled nursing facility can answer many of the questions you may have about advance care planning. Most organizations have educational brochures that explain medical interventions that are usually addressed in a healthcare directive. Some organizations have professionals who are trained as Advance Care Planning Facilitators. Competency of these individuals has been certified using evidence based training processes. Ask your health system whether they have a certified ACP Facilitator who can assist you with identifying your preferences and writing your healthcare directive.

Advanced Care Planning of North Dakota

Advanced Care Planning of North Dakota is collaborative organization working on a statewide initiative to improve advance care planning. More than 119

individuals representing various professions and organizations are participating in this effort.

Priorities: The following four priorities were identified to accomplish the goal of implementing a comprehensive advance care planning program:

1. Identify the model the best suits a rural state.
2. Organize as a non-profit entity.
3. Identify a standardized medical order form for advance care planning.
4. Establish a presence in North Dakota.

For more information contact Nancy Joyner, President on the ACP ND Board of Directors. You can reach her at njoynergf@gmail.com or (701) 746-472

This is general information and should not be interpreted as legal advice. Contact an attorney to discuss your specific situation.