

Advance Care Planning and Advance Directives

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When it comes to end-of-life decisions, planning and communication can make a big difference. The place for these difficult conversations should **not** be in the Intensive Care Unit (ICU). They should be held at the kitchen table or living room couch, long before the time comes to implement them. As a patient, you can take power over the decisions about how you will die. Without these directions, your family will make these difficult decisions without your input. The decision may not be what you or they want. This is not an easy conversation for patients, families, or healthcare professionals but it is a necessary one.

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What is advance care planning?

Advance care planning is your chance to make decisions about the care you want to receive at a time when you might be unable to speak for yourself. It is a process that involves you, your family, loved ones, and healthcare providers. The goal is to maintain and maximize your health and independence as you face the end of life. It should be a compassionate process, with support and education as your health changes. As a congenital heart patient, knowledge of your congenital heart defect (CHD) and what relevant information you need to adequately complete the process is important. Your advance care plan is not a one and done process. It should be reviewed over time as your health and decisions change. Advance care planning includes completing advance directives so that your wants are documented.

What are advance directives (ADs)?

An advance directive is a written statement of what type of medical treatment you want at the end of life. It confirms that your wishes are carried out if you are not able to communicate them to a healthcare professional. Advance directives are an ongoing process that can change over time. Legally valid throughout the United States, laws governing them vary in each state. It is important to make sure you are using the correct forms for the state in which you reside. The term “advance directive” includes patient-initiated documents,

such as a living will and a durable power of attorney and physician initiated medical orders, known as a POLST or MOLST.

A living will is a legal document that you create. It can be a written or a video statement about the kinds of medical care you do or do not want to receive if you are no longer able to express your consent. This includes things such as resuscitation, desired quality of life, and end-of-life treatments, among other things. When creating a living will, you should know how independent you want to be and what you want out of your life. Do you want your life extended for any reason or only if a cure is possible? Having treatment or not having treatment is your decision. Nothing is right or wrong. This is your choice. Once you have a living will, discuss and share it with everyone. This includes your family, your primary care doctor, your proxy, your adult congenital heart disease (ACHD) cardiologist, and your friends. It is important to keep a copy with all of your important papers. It's also a good idea to keep a wallet card with you that tells people you have advance directives and always carry a copy when traveling.



A healthcare proxy or durable power of attorney for healthcare is a document that lets you appoint another person to make your healthcare decisions if you cannot speak for yourself. In other words, you are choosing someone to have the power to act in your place. This cannot be your doctor. A healthcare proxy does not expire but the appointed person can resign at any time or you can fire him/her. Healthcare providers have to follow your healthcare proxy as if it is you. A healthcare proxy does not have to be notarized but it should be

written, signed and dated with two witnesses and include instructions. A durable power of attorney for healthcare can never contradict the terms of your living will.

Rather, that person is there to fill in gaps, for situations not covered by your living will, or in case your living will is invalidated for any reason.

Medical orders for life-sustaining treatment (MOLST) are sometimes called POLST (Provider Orders for Life Sustaining Treatment). These documents contain the medical orders that will be used for treatment when you are at the end of life. The document is created with and signed by your healthcare professional with your input. It contains legal medical orders that will be used with your living will and other advance directives to guide your family and doctors in providing care if you are unable to make your own decisions.

When is the best time to talk about advance care planning and advance directives?

At the age of 18, you are legally an adult and as such, it is assumed you are competent to make healthcare decisions and know the risks and benefits of treatment and financial decisions. However, this is frequently not the case.

For this reason, it's important that this conversation happen before you become an adult. It should start while your parent(s) are your legal guardian—before your 18th birthday. The necessary papers should be in place by the time you turn 18.

Why is this discussion important in congenital heart disease?

This discussion is important for a variety of reasons. In 2012, in the *American Journal of Cardiology*, Tobler and others reported that only 5% of CHD patients had completed advance directives and 56% did not know about them. 87% of those surveyed stated that advance directives were important but just 19% had identified a surrogate or healthcare proxy. That same year, in *Palliative Medicine*, Tobler also stated that 50% of ACHD patients die in the hospital. Of these, two-thirds die in the intensive care setting and almost a half were on life support. Only 10% of patients in ACHD care had an end-of-life discussion.

Why does this happen? Many ACHD patients and even some healthcare professionals assume adults with CHD

are “cured” and have a “normal” lifespan. We now know this is not true. Mortality has shifted to adulthood in CHD patients. Yet, many of the “miracle” outcomes still die young.

Why don't ACHD providers talk about this? There are a number of reasons. First, healthcare providers and patients alike do not communicate well about end-of-life decisions. Professionals do not reflect on the reality of the advanced disease and end of life. Even when appropriate, often ACHD cardiologists don't refer their patients to palliative care providers. No plans are made to deal with decline in the health of the patient since most providers are not adept at handling such discussions.

What are the challenges to advance care planning?

One challenge to effective advance care planning is that many people are afraid of facing illness and death. This includes healthcare providers who aren't trained to talk about it and are uncomfortable talking about it. Patients and families also have a hard time bringing this topic up to each other and to their doctors. If families and/or healthcare professionals don't know the wishes, values and beliefs of a person prior to serious illness, it is usually because they have not been asked.

Another challenge occurs when there is conflict between the values of family members and/or healthcare providers. Confusing terminology and vague instructions can make for a difficult conversation. It's important to use words that everyone understands. Lastly, the discomfort of healthcare providers and the fact that they do not have the right tools to help patients and give them appropriate answers about their prognosis can often become challenging.

What are the benefits to effective advance care planning?

Having advance care directives reduces anxiety about what is going to happen at the end of your life. Having a sense of control over what might happen in the future can give you comfort. It also provides an opportunity to avoid unnecessary conflicts between family members and healthcare professionals at the time of your death. To reduce these gaps in care, empower yourself by talking to your ACHD provider about end-of-life decisions and take charge of your life and death. It is important to have a plan in place.

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