

Advance Care Planning and Palliative Care

For congenital heart patients

This section of the Congenital Heart Conditions notebook explains advance care planning and palliative care.

What is advance care planning?

It is always your choice whether or not to have certain types of care. But, there may be times when you are not able to tell your doctors what kind of care you want. This could happen if you become very sick, or you cannot speak for yourself for some reason.

Advance care planning lets you make decisions about the care you may want to receive at these times. Advance care planning gives you control over what might happen to you in the future. This can help ease anxiety.

It is best to do advance care planning before you become ill. As your health status and decisions change over time, you can review and update your care plan.

Care choices are very personal. Talk with your family, your loved ones, and your healthcare provider about what you want.



Talk with your loved ones and provider about your wishes for your care.

What is an advance directive?

An advance directive is a written form that tells your doctors and loved ones what care you want. It helps make sure that your wishes are carried out if you are not able to tell your care team what you want. There are different kinds of advance directives (see page 2).

Advance directives are legal documents. Each state has its own laws about how they are used. **Make sure you are using the right forms for the state where you live.**

Once you fill out an advance directive, share it with your family, loved ones, and care providers. Keep a copy with your other legal documents. You can change your advance directives over time, if you wish.

What are some kinds of advance directives?

- A **living will** is a legal form. It tells the kinds of medical care you do or do not want to receive if you cannot express your wishes. It tells your loved ones whether you want to receive resuscitation, surgeries, end-of-life treatments, and other treatments.
- You can use a **durable power of attorney** or **healthcare proxy** to appoint another person to make decisions about your healthcare if you are not able to speak for yourself. This person helps with decisions that are not covered by your living will. But, your proxy cannot do anything that goes against your living will. Healthcare providers must follow the decisions of your proxy as if you were making the decisions.

Your proxy cannot be your doctor. You can change your proxy at any time, if you wish.

What is palliative care?

Palliative care is special type of care for people who have a serious illness. It helps provide relief from the symptoms and stress of having a serious illness. Its goal is to improve quality of life.

Patients and their loved ones can benefit from palliative care at any stage of a serious illness. Palliative care can include hospice, but this is only one of many types of support you can ask for.

Talk with your provider about palliative care. If needed, they may refer you to our Palliative Care team.

When you talk with a member of our Palliative Care team, you can ask about ways to ease your symptoms or cope with stress. You can also talk about your healthcare goals and make decisions about treatments.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Heart Institute Adult Congenital Heart Disease Program: 206.598.1764

To Learn More

- Adult Congenital Heart Association: www.achaheart.org/media/2055/qandaadvancedcareweb.pdf
- Center to Advance Palliative Care: <https://getpalliativecare.org>
- Conversation Project: <https://theconversationproject.org>

Empower yourself by talking to your ACHD healthcare provider about advance care planning and palliative care!