



**TEAM UNCLE JOE**  
— Navigating CHD —

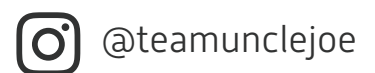
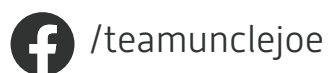
TeamUncleJoe.org



# **ADVANCED CARE PLANNING WORKBOOK**

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A Resource for ACHD Patients



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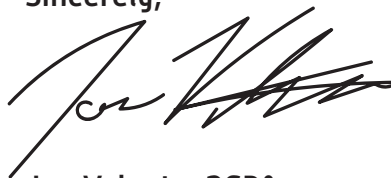
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**Dear ACHD Patient,**

If you get stuck at any time during your advanced care planning, we are here to walk you through the process. Remember, these decisions are yours. While family and those close to you play an essential role in your advanced care plan, at the end of the day, your autonomy is still crucial and must be upheld throughout this process. As CHD patients and patient navigators, we understand the challenges and realities of advanced care planning, and we want you to know you are not alone in this process.



Sincerely,



Joe Valente, BCPA

## Introduction

Before we begin in earnest, we must define a few terms and explain a few things to be on the same page. Some of these terms can be confusing as they have very similar names but mean very different things, so pay careful attention to the following section. Also, some people will use different words for the same terms, so you will need to understand the synonyms for these as you navigate your way through your healthcare journey.

### What is an Advanced Directive?

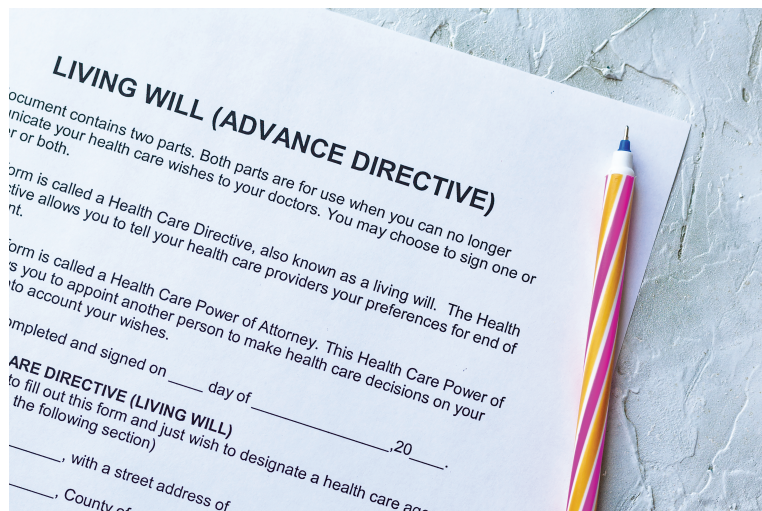
An advanced directive is a legal document that tells your family and doctors what medical care you would want if you are unable to speak for yourself and they are required to make decisions on your behalf.

### What an Advanced Directive is Not

An advanced directive is not a Do Not Resuscitate Order or DNR. However, an Advanced Directive can include a DNR if you wish.

### Will vs A Living Will

A will is a document executed upon one's death and usually involves the distribution of assets. A living will is another name for an advanced directive. The document gives directions to loved ones and doctors about medical care when one is still alive but unable to communicate their wishes themselves. *[Note: This workbook only covers living wills].*



### Power of Attorney vs Medical Power of Attorney

Power of attorney grants someone power over your financial, legal, and business interests. In contrast, a Medical Power of Attorney gives someone the power to make critical medical decisions on your behalf if you are unable to do so. *[Note: This workbook only covers Medical Power of Attorney].*

**Advanced Care Plan (synonyms):** Living Will, Advanced Directive, Directive to Physicians

**Medical Power of Attorney (synonyms):** Durable Power of Attorney for Healthcare, Healthcare Proxy, Healthcare Agent, sometimes informally referred to just as proxy or agent.

## Part: 1 Overview

We designed this workbook to help you think about the types of care you would want in planning to talk to your family and prepare your advanced care plan. An advanced care plan involves decisions that you would like to be made for you when you cannot make them for yourself. We will get into the specifics later, but this often does not mean end-of-life care. Many patients need someone to speak for them for a period of time until they can speak for themselves again, so we should approach this process with an open mind about the outcome.

In creating this workbook, we did so with special thought given to the Adult CHD patient, especially the procedures and challenges faced by this patient population. The goal of any advanced care plan is to take the decision-making out of the hands of the healthcare proxy by making it known what the patient wanted before they became incapacitated. The goal of this workbook is to help you think through what you would want and make sure it is communicated effectively in your advanced care plan and to your loved ones.

As an adult CHD patient you are significantly younger than the average patient the first time you will fill out your advanced care plan. This workbook pays special attention to those details. Not only will you have a higher likelihood of only being temporarily incapacitated, but you may also face some of the medical interventions listed herein at some point in your life. Walking through this workbook will prepare you for those major events if they happen to arise, no matter who is making the decisions.

Some of the treatments listed here like, heart transplant, may not be seen in other advanced care planning guides. But many treatments listed herein are bridges to transplant; therefore, we believe it is essential that your family and doctors know your wishes for transplant and these other treatments. Furthermore, this is an excellent time for you to think about things you would want if you were the one making the decisions instead of being thrust into them in a time of crisis.

## Goals of this workbook

- Understand what an advanced care plan is.
- Think about what is important to you in your life.
- Start the conversation with your loved ones and doctors.
- Setting the framework for understanding advanced treatment options.
- Ultimately to complete your advanced directives and other documents to record your decisions.

## Things to remember about your Advanced Care Plan:

**1. It is a living, breathing document.** You will change how you feel about things over time, and it is okay to change your advanced directive. In fact, you should be reviewing it regularly. Review it no less than once a year. We recommend examining before your annual cardiology appointment or another annual milestone. Make a habit of it.

**2. This topic can be exhausting; take a break.** That could mean an hour or a few days. Give yourself space to think about your wishes without the pressure of actively working on this workbook or your directive.

**3. Get others involved in the process early on.** Do not wait until you have the document notarized to review it with your doctors or loved ones. This process should be open and iterative and involve your entire team. However, remember the final decisions are yours.

**4. Set some goals.** We realize this is a challenging subject to approach and a tough task to complete. So set some realistic goals and get it done. We recommend 4-6 weeks and schedule it around a time you have a cardiology appointment or other appointments.

## What makes a good Advanced Directive?

A good Advanced Directive should be clear as to your wishes and attempt to take the choices out of your family's hands when they are making the decisions for you. To accomplish this, you should talk with your family about your wishes and be thorough in completing your directive and make every attempt not to leave anything out. Remember, they will be making these decisions in hard times, do not leave them guessing. Doing a complete advanced care plan can reduce disagreement between your loved ones, and ultimately they will be able to honor your wishes.

## Part: 2 Building Your Team

### Choosing your Healthcare Proxy

Our number one rule to helping you choose your healthcare proxy is to choose your healthcare leader, not your emotional leader. People often worry that others may be offended that they didn't choose them to be their proxy, but choosing your healthcare leader will help your emotional leaders and you get through the process better.

#### How do I know who my healthcare leader is?

*(Ask yourself several questions before deciding who your healthcare leader is)*

Who do you call to discuss your latest doctor appointment or medical concerns?

Who has a medical background or credentials?

Who has the best clinical skills on your team?

Who knows your medical history and condition best?

Who do you feel most comfortable with making your decisions?

Could you talk to this person and become comfortable with them making your decisions?

### Reviewing your Advanced Care Plan with you Doctor

When it comes to reviewing your advanced care plan with your doctor, there is one question you should ask your doctor, "could you make decisions for me based on this document?" Most doctors will tell you that when they have had to rely on an advanced directive, they didn't know what the patient wanted. Your goal when discussing your advanced directive with your medical team is to make sure that they understand your plan and can act in your best interest. Hopefully, through the steps in this handbook, we will get you most of the way there.

Of course, you will need to ask them any other questions about specific medical procedures or other concerns that you may have. However, we recommend exhausting all your options researching those through valid resources first so you can best utilize your time with your team and ask productive questions. We provide some resources in this workbook for you to do further research on particular treatment options if you need them.

## Part: 3 Quality of Life

The following questions concern the time at which you would be unable to make decisions for yourself. There is no correct answer and no right way to approach it. These questions are here to get you thinking about the things that are important in your life.

What beliefs do you have that impact your decision-making? What are those decisions? *i.e. religious beliefs*

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What is your biggest concern about not being able to make decisions for yourself?

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What is your biggest worry when you wake up?

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### Quality of Life

What do you value most in your life?

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What does a good quality of life look like to you?

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### Rate from 1 to 5 (1 most important)

- Not being reliant on someone else.
- Being able to talk.
- Being able to walk.
- Not being reliant on an external device.
- Being able to spend time with family.

- Living as long as possible no matter what.
- Ability to communicate in some way.
- Having some control over my life.
- Ability to eat.
- Ability to work.

## Part: 4 Treatments

Are there any treatments that go against your religious or spiritual beliefs? If yes, what treatments?

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### Breathing Support

#### BiPAP or CPAP

**What it is-** a form of non-invasive ventilation used to support your breathing through a mask or helmet. BiPAP alternates the amount of air on the inhalation vs. exhalations, while CPAP is a continuous pressure.

#### Resources:

<https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/bipap>

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#### Preferences:

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#### Questions for my team:

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### Intubation & Mechanical Ventilation

**What it is -** Mechanical ventilation is a form of life support. A mechanical ventilator is a machine that takes over breathing when a person cannot breathe on their own, reducing the work needed to stay alive. Intubation is the procedure used to place the tube down your throat and into your windpipe to make it easier to get air in and out of your lungs. The mechanical ventilator, often just called a ventilator, vent, or respirator is hooked up to this tube and pumps air and oxygen into your lungs.

**Resources:**

<https://www.thoracic.org/patients/patient-resources/resources/mechanical-ventilation.pdf>

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**Preferences:**

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**Questions for my team:**

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**Tracheostomy - Long-term Intubation and Mechanical Ventilation**

**What it is** - A tracheostomy is an opening created in the front of your neck and windpipe such that a tube can be inserted into your windpipe. This tube can then be hooked up to a ventilator to supply you with mechanical ventilatory support. However, a ventilator is not always a requirement of a tracheostomy.

**Resources:**

<https://www.mayoclinic.org/tests-procedures/tracheostomy/about/pac-20384673>

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**Preferences:**

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**Questions for my team:**

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## Circulatory Support

### ECMO

**What it is** - ECMO stands for extracorporeal membrane oxygenation. It is a process by which blood is pumped outside your body through a heart-lung machine that removes the carbon dioxide and sends oxygen-filled blood back to the body. ECMO is primarily used to take the workload off the heart or lungs, thereby allowing them to heal. ECMO is a short-term treatment usually on the measure of days to weeks.

#### Resources:

<https://www.mayoclinic.org/tests-procedures/ecmo/about/pac-20484615>

<https://www.ucsfhealth.org/treatments/extracorporeal-membrane-oxygenation>

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#### Preferences:

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#### Questions for my team:

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## LVAD

**What it is** - LVAD stands for left ventricular assist device, and it is a mechanical pump implanted in patients with heart failure of the left ventricle. It works by assisting your left ventricle in pumping blood through the aorta and out to your body. An external battery pack powers an LVAD, and often patients can leave the hospital with these devices. Furthermore, an LVAD can be a bridge to transplant or a destination treatment if a transplant is not viable.

#### Resources:

<https://stanfordhealthcare.org/medical-treatments/l/lvad.html>

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**Preferences:**

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**Questions for my team:**

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## Total Artificial Heart

**What it is** - A total artificial heart (TAH) is a surgically implanted pump to replace the heart's diseased ventricles. Batteries and machines outside the body control the pump. A TAH is often used if you are in heart failure and need long-term support.

**Resources:**

<https://www.nhlbi.nih.gov/health-topics/total-artificial-heart>

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**Preferences:**

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**Questions for my team:**

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## Heart Transplant

**What it is** - A heart transplant is often used at end-stage heart failure, and it comes with its own set of risks and complications. A heart transplant happens when a recently deceased organ donor donates their heart, and it is a match for the patient it is being implanted into.

**Resources:**

<https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/heart-transplant>

<https://www.heart.org/en/health-topics/congenital-heart-defects/care-and-treatment-for-congenital-heart-defects/heart-transplant>

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**Preferences:**

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**Questions for my team:**

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## Cardiopulmonary Resuscitation

**What it is** - Cardiopulmonary resuscitation, or CPR, is an emergency procedure that combines chest compressions and usually artificial ventilation. This is an effort to manually preserve intact brain function until further measures are taken to restore spontaneous blood circulation and breathing in a person who is in cardiac arrest.

**Resources:**

<https://www.redcross.org/take-a-class/cpr/performing-cpr/cpr-steps>

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**Preferences:**

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**Questions for my team:**

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## Artificial Nutrition and Hydration

**What it is**- Artificial nutrition is the delivery of a patient's nutrition support by means of bypassing the need to chew or swallow. Artificial nutrition can be achieved with a nasogastric tube (NG tube), a gastrostomy tube (G-tube or PEG) or via total parenteral nutrition (TPN). Artificial hydration usually refers to IV-based hydration measures, like saline, used when the patient cannot swallow fluids on their own.

**Resources:**

<https://www.uofmhealth.org/health-library/tu4431>

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**Preferences:**

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**Questions for my team:**

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**Dialysis**

**What it is-** Dialysis is performed when the kidneys are not functioning correctly. Dialysis is a procedure to remove waste products and excess fluids from the blood. It does not treat the kidney condition; it simply performs some of the kidney functions for the patient. Dialysis can be short-term in the case of acute kidney injury or long-term in kidney failure.

**Resources:**

<https://www.nhs.uk/conditions/dialysis/>

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**Preferences:**

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**Questions for my team:**

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**Organ Donor**

Most state-specific advanced directive forms will have a check box for organ donation; that is to say, if you do die, you would like your organs or tissues to be donated. In addition to that checkbox, we believe you should add some language in your advanced directive about your wishes about organ donation.

## Part: 5 Sample Language for Advanced Directives

Now comes the challenging part of pulling this workbook, your thoughts, and feelings about your wishes into language that communicates your wishes appropriately. There is no one way to do this, but we will give you a few examples to get you started. First, make sure that you use a state-specific form to start your advanced directive. You can find them at <https://bit.ly/3EAPurv>. Secondly, you more than likely will need to attach an additional page to your state's form to fit your directive on it.

After starting your state-specific form, we would work through this workbook from Part 3 and 4 and write out any information that you think is relevant for your family and doctors to know. Remember, we are trying to make the decision-making process as easy as possible for them if this document is ever needed to be used.

**This might look something like this** (*these are just examples*):

### General Health & Quality of Life

*Any healthcare decisions should be made around my quality of life. My independence is the most important thing to me, and I would not want to extend my life if I could not be independent.*

*My family is the most valuable thing to me, and I want everything possible to be done to keep me alive so that I can spend more time with them regardless of the outcome.*

*Having some control over my life is important. I would not want to live if I had to be cared for full-time.*

*I don't want to be reliant on an external device for an extended amount of time. I would only want it if it were bridging to another long-term treatment.*

*I would not want to live if I could not communicate by voice, computer, or sign language.*

## **Specific Treatments**

*My life would not be worth living if I had to be kept on a ventilator indefinitely.*

*I think ECMO is a viable treatment option, and I want it under any circumstances.*

*I want CPR under any circumstances.*

*I think nutrition and hydration are basic necessities and should be provided by any means necessary to keep me alive.*

*I would accept the use of an LVAD as a bridge treatment but not as a destination therapy.*

*I believe in the use of a heart transplant to treat end-stage heart failure. I would want everything possible done to bridge me to a heart transplant.*

*Do not start or continue life-sustaining procedures if my condition is unlikely to improve and I am not expected to return to a full independent functional capacity.*

**If it makes sense to do so, you can also combine treatments into one specific line item. That might look something like this:**

*I believe in the use of mechanical circulatory support in most circumstances, including the use of LVAD, ECMO, and a total artificial heart.*

**OR**

*I believe in the use of mechanical circulatory support as a bridge treatment but not a destination treatment, including LVAD and a total artificial heart.*

## **Organ Donor**

*I believe that my organs and tissues are of no use to me after I am deceased; therefore, I want my organs and tissues donated to someone else.*

*I want all my major organs donated, but I do not feel comfortable donating my eyes or tissues.*

**Please send any questions to: [questions@TeamUncleJoe.org](mailto:questions@TeamUncleJoe.org)**

# OUR MISSION

“To equip Congenital Heart Disease patients and their families with the resources and information needed to thrive.”



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