PATIENT EDUCATION | *INFORMATION SERIES*

Making Decisions about Serious Illness: What Is Code Status?

Making decisions about life support and other medical care if you are too sick to speak for yourself is called advance care planning. This involves talking to your family, friends, and medical team about your wishes, including something called a "code status". This fact sheet reviews the parts that make up advance care planning and steps you can take to let your family, friends, and doctors know about your wishes during a severe illness so you receive only the kind of treatments you want.

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What is code status?

In order for the human body to work correctly, the heart has to pump blood to all the organs and the lungs have to get oxygen into the blood and carbon dioxide out of the blood. If the heart stops beating, it is called "cardiac arrest." If a person stops breathing, it is called "respiratory arrest." If the lungs are not able to get enough oxygen into the blood or carbon dioxide out of the blood, it is called "respiratory failure." A person whose heart and lungs have stopped working has died.

Death is a very personal matter for everyone. Some people have decided that they do not ever want any form of artificial life support while others want to go on artificial life support to give doctors time to try and fix things. Sometimes people want to try artificial life support for a short time but stop if doctors aren't able to find fixable problems or if they get sicker. Picking a code status that aligns with your values is part of a process to make decisions about your healthcare in case of serious illness.

When you are admitted to the hospital, your code status is an instruction from you to your medical team about what the medical team should do if you have a cardiac or respiratory arrest. It is routine for the medical team to ask all patients about their code status when they are admitted to the hospital. Unless you tell the team otherwise, full resuscitation will be performed by the medical team if you have a cardiac or respiratory arrest.

What is resuscitation?

Resuscitation is a group of procedures to do the work of the heart and lungs if you have a cardiac or respiratory arrest while the medical team tries to figure out why your heart or lungs stopped working. These steps can include:

Cardiopulmonary resuscitation (CPR): CPR means doing compressions, or strong pushes on the chest, to do the heart's job of pumping blood to vital organs while the medical team tries to figure out why the heart stopped. Even the best CPR can only do about one-third of the work of the heart, so vital organs such as the brain and kidneys can be permanently damaged from not receiving enough blood flow. Only about one quarter of patients who receive CPR survive to leave the hospital and some may have permanent brain or other organ damage.

Intubation: The lungs bring oxygen into the body and get rid of carbon dioxide so vital organs keep working. When a person cannot breathe, a machine called a ventilator can be used to do the lungs' job. A tube is put through the mouth into the windpipe and connected to a ventilator as a type of artificial life support. Ventilators do not cure the lungs, and can increase the risk of complications like lung infections, so doctors only use them if the lungs are too sick for the body to survive without support.

Defibrillation: An abnormal electrical rhythm in the heart can cause cardiac arrest. Defibrillation means giving an electric shock to the chest to try to reset the heart to a normal rhythm.

Administration of medications: When a person develops cardiac arrest, the medical team may use medications, like epinephrine, to try to help the heart begin beating again.

What are types of code status?

Full Code: This means that if you have cardiac or respiratory arrest, the medical team will perform all the procedures described above if needed. Being "full code" may be helpful if you have a treatable problem that led to cardiac or respiratory arrest. CPR is usually not recommended for a person who is already very sick with an incurable disease because it is unlikely to be effective.

Do-Not-Attempt-Resuscitation (DNAR): This means choosing to NOT have CPR. Having a DNAR order in place means that if your heart stops beating, the medical team will not perform CPR or defibrillation, or give you medications to try and make your heart beat again.

Do-Not-Intubate (DNI): This means choosing to NOT be connected to a ventilator if your lungs aren't working.

I am OK with being on a ventilator but not with receiving CPR. Is there a code status for me?

Yes. You can ask that your body be supported with a ventilator if your lungs are failing, but that if your heart stops, you can die naturally. This DNR/OK to Intubate code status means

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that if your heart stops you do not want resuscitation but will accept a ventilator for respiratory arrest or failure.

I never want to be on a ventilator, even for a short period, but I want my heart restarted if it stops. Is there a code status for me?

Being connected to a ventilator is part of the resuscitation process. This code status is not recommended nor offered in many hospitals. If you feel strongly about this, talk to your medical team to see what options exist.

If I choose DNAR/DNI, does this mean I am giving up?

No. While your heart continues to beat, and your lungs continue to work, a DNAR/DNI status does NOT keep you from getting other treatments to prolong your life. You can discuss with your medical team what kind of life-prolonging treatments you are willing to accept, including things like antibiotics or hemodialysis. Code status does not affect your ability to receive high-quality care.

How will doctors know what I want if I am too sick to speak?

You can prepare a legal document called an "Advance Directive," which may include a 'living will'. In some states, there are also Physician Orders for Life-Sustaining Treatment (POLST) forms. These documents can include your wishes for code status and treatments you may or may not want, such as dialysis, artificial feeding, or organ donation. Even if you do not prepare legal documents or complete forms, it is very important to discuss your thoughts about life-sustaining treatments with your friends and family members because the medical team will rely on them to express your wishes if you cannot do so yourself.

Who will my doctors speak to if I am too sick to speak to them myself?

You can name a person who you want to make your healthcare decisions for you if you are unable to speak for yourself and list them in your advance directive. This can be anyone who understands your wishes and could talk to the doctors on your behalf if you were too sick to do it yourself. The title of this person varies by state, but they may be known as your Medical Power of Attorney (MPOA), Durable Power of Attorney for Health Care (DPOA-HC), or your Healthcare Proxy. This designated person will only make medical decisions if you are unable to make decisions for yourself.

Who will my doctors speak to if I have not picked someone to be my decision maker?

Your doctors will reach out to your loved ones to act as "surrogate decision-makers" who can tell them your wishes or speak with them about your values and how those might inform choices about your care. The people who are able to serve as a surrogate decision-maker differs by state. In general, the team will first talk to your spouse, adult children, parents, siblings, and in some situations, close friends. If no one can be identified to act as your surrogate decision-maker, the medical team will need to follow guidance from their state regarding next steps. In some cases, two doctors involved in your care can legally make decisions on your behalf while in other states, a legal guardian may be appointed by the court.

How can I make sure the team knows my treatment preferences if I end up in the hospital?

Your healthcare provider, including a doctor, nurse practitioner or physician assistant, can help you complete a Physician Orders for Life-Sustaining Treatment (POLST) form. This is a medical order that lists specific treatments you would or would not want if you became sick, such as dialysis or artificial feeding. It must be signed by both you (or your designated decisionmaker) AND your doctor, nurse practitioner, or physician assistant.

I do not want CPR. How will paramedics know this if I have an emergency outside the hospital?

If someone has an emergency in their home, paramedics on the scene will perform CPR unless they are provided with documentation that you did NOT want CPR. Two documents allow them to legally withhold CPR: a POLST form or an out-of-hospital DNAR form. If you do not want CPR, you and your healthcare provider can fill out a POLST form or an out-of-hospital DNAR form. You can place this form somewhere in your home which is easy to access, like on your fridge, where paramedics know to look for it.

What if I want to change my code status?

You can revise your advance directive or POLST form, or, if you are in the hospital, verbally let your medical team know at any time if you want to change your code status.

Action Steps:

- ✔ Think about what is important to you and what kind of care you would want if you became seriously ill.
- ✔ Pick a person to make your medical decisions on your behalf and let them know your wishes.
- ✔ Talk to your primary care doctor about your healthcare decisions and fill out an advance directive or a POLST form.
- ✔ If you do not want CPR, talk to your doctor about a POLST form or out-of-hospital DNAR and stick it on your refrigerator where paramedics can see it in an emergency.

Healthcare Provider's Contact Number:

Authors: Nehan Sher, MD, Naomi Habib, MD, Shiri Etzioni, MD, Marilyn Glassberg, MD
Reviewers: Catherine Chen, MD, Ann Jennerich, MD, ATSF, Marianna Sockrider MD, DrPH

Resources:

National POLST
- https://polst.org/

The Conversation Project
- https://theconversationproject.org/wp-content/uploads/2020/12/HealthCareTeamGuide.pdf

American Thoracic Society
- https://www.thoracic.org/patients/resources/managing-the-icu-experience.pdf

Our Care Wishes
- https://www.ourcarewishes.org/

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