

A Decision-making Guide for Patients, Families and Caregivers



Hope is the thing with feathers that perches in the soul and sings the tune without the words and never stops at all

Emily Dickinson

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Introduction

This pamphlet provides you with information to answer important questions that you as a patient, family member or caregiver may have about the term "resuscitation". Resuscitation is the word used to describe the actions that are taken to attempt to bring a person back to life when he/she has stopped breathing or his/her heart has stopped beating.

Why does a person's breathing stop?

Why does a person's heart stop beating?

There are many circumstances that can cause someone's breathing or heart to stop (often referred to as cardiopulmonary or cardiorespiratory arrest). Sometimes it is because of an unexpected event such as a sudden heart attack, stroke or an accident. Other times it is what naturally occurs at the end stage of an illness that medicine is unable to cure. Either of these situations can be upsetting for people to deal with and to talk about. However, since everyone's heart and breathing will one day stop (the point at which a person dies), being able to talk about these issues, may ease the stress that accompanies the process.



What is CPR?

CPR, or **C**ardio**P**ulmonary **R**esuscitation, refers to the medical procedures that may be performed in an attempt to restart a person's heart and breathing. CPR may range from efforts, such as helping the person to breathe and repeated pressure applied to the chest, to more complicated measures. The more complicated procedures may only be available in specific settings where skilled staff and equipment are present. Therefore, it may be important to talk with your health care team if you want more information about what is available in your setting.



CPR, like any other treatment, will be available as a treatment. option if the doctor believes that performing it may benefit the patient—that is that the doctor believes the person's health may improve after it is performed. If the doctor does not offer CPR as a treatment option, it is because he/she believes that the person's health has almost certainly no chance of improving and that the treatment will cause more harm than good. This means that even if a person wants CPR performed, the doctor may not be required to offer it.

What is DNR?

DNR is short for "**Do Not Resuscitate**" – an instruction given to health care providers telling them not to perform CPR if a patient stops breathing or his/her heart stops beating. This instruction can be provided:

- 1. by a patient in advance, usually as a verbally stated or written wish (known as an advance directive) to a member of the health care team,
- 2. by a substitute decision-maker, as verbal or written consent to the health care team, on behalf of a patient who is unable to make decisions for him/herself,
- 3. by a physician in the form of a written order.

Health care providers are automatically required to perform CPR on a patient whose heart and/or breathing has stopped, unless they have received an instruction for DNR by one of the methods described above. But, it is important to know that if CPR is available, as with any treatment, it doesn't mean that one is required to receive it. Therefore, as a patient (or substitute decision-maker on behalf of a patient), if you know that you do not want CPR (i.e. you want a DNR), it is important that you tell your health care providers so they know what your wishes are.

When one of the above three instructions for DNR has been received, the term DNR will be written in the patient's health care record to ensure that all members of the health care team are aware of what is to be done if the patient's heart and/or breathing stop.

Health care providers understand that most people do not want to die and that it can be hard to accept not doing everything possible to stay alive. Accepting a DNR does not mean that other treatments will be stopped or that they won't be offered. Even when death may be unavoidable there are always things that health care providers can do to help a person. Regardless of your situation, *all* people at *all* times have the right to high quality care that aims to keep them comfortable.



Is it ethically acceptable to have a DNR?

It is widely recognized by health care professionals, clergy, lawyers and others that there are many ethical issues that need to be considered when making decisions about resuscitation. These groups generally agree that, depending on the situation, having a DNR may be a very ethical way to deal with a medical situation in which cure does not seem possible. Each situation is unique and therefore needs to be dealt with on its own.

"Yet, even with serious illness, there may yet be golden days you will never forget."

Earl A. Grollman

Health Care Providers in Our Community

are committed to the provision of personalized care that supports people to maintain their health, maximize their quality of life, and preserve their dignity at all times. They believe in:

- using open honest communication with patients and families and
- respecting with wishes of patients in health care decision-making

As part of a routine admission process, you may be asked to state what you (or your substitute-decision maker on your behalf) would like to have done in the event that your heart and breathing stop.



situations change, if you are already receiving Because health home, hospice, hospital care long-term (at or home) and your condition begins care to worsen, your health care providers may talk to you about your wishes, (or your substitute-decision maker about what you would want done on your behalf).

Knowing how difficult it is for people to receive sad news, your health care providers often find it very hard being the ones to share it. Trust that they want to support you and to prepare you for whatever may happen.

How do I decide?

It is common for people to have difficulty making a decision about resuscitation. Sometimes the "right" decision is obvious but other times it may be unclear.

A decision about resuscitation is usually made cooperatively based on what doctors think is the right thing to do and what you value as a patient and family.

Below are some factors to consider in making a decision.

1. Be realistic: As difficult as it may be, try to be realistic about the chances that resuscitation will be successful. Is cure possible, or will you (or your loved one) be returned to a state of disease that remains unchanged or has worsened? Usually, only people who are relatively healthy that suffer a sudden emergency and have CPR performed, are successfully returned to a healthy condition.

People living at the end-stage of irreversible disease have a very poor chance of being able to maintain their own heartbeat and breathing after CPR has been performed. In these circumstances, when CPR is done, it does not reverse the disease process. The person still has the same disease that they had prior to CPR being performed.

And, whether CPR is successful or not, since it is an invasive procedure, it will almost always result in some harm to the body.

How do I decide? (Cont'd)

- 2. Substitute Decision-making: Patients, if they are able to make decisions for themselves, are permitted by law to do so. If they become too ill and cannot, someone else called a "substitute decision-maker" (SDM) will make decisions for them. SDMs are required to make decisions that are the same as what a patient would choose for him or herself. Therefore, as a patient, it is important to select a SDM and to discuss with him/her your wishes. If you have further questions about how SDMs are selected or their role, your health care providers will be able to answer your questions or can direct you to someone who will.
- **3. Family**: It can be helpful to talk as a family about resuscitation and to have agreement about what the right decision is. By doing so, if the person's breathing or heart stops suddenly, everyone in the family will know what will be done at the time. Having everyone on the "same page" helps to minimize the risk of conflict between family members.

If you and your family are not in agreement about what the right decision is, it can be helpful to meet together to discuss the issues in more detail. If you choose to have a family meeting, you may want to have it facilitated by someone who is skilled at assisting families through these kinds of difficult situations, someone like a social worker and/or chaplain. Other members of the health care team may also need to attend, such as your doctor and nurses.





How do I decide? (Cont'd)

- 4. Be Prepared: It is human nature to wish that a bad situation may not be as bad as it is. As a result, people may not want to address problems until they absolutely have to. If you or your loved one is living with serious illness, not addressing the issue of resuscitation, doesn't make it go away. It is better to be prepared in advance by understanding as fully as possible what you want to do about the situation you are in.
- 5. Talk with your health care providers, including your doctor and nurses. Since they have been trained to determine the potential benefits and risks of CPR, try to listen to what they have to say. However, it is also important that they understand what your values are as a patient and family. Hopefully together a decision can be made that everyone can accept.

If CPR is a treatment option that is available to you, tell your health care providers what you would like to have done e.g. "Please do CPR" or "Please do not do CPR". Remember, if they do not know what your wishes are, medical procedures may be performed that you would not want. For loved ones, this can be especially difficult if they observe CPR being performed against your wishes.

Can I change my mind?

As a patient, if CPR is available to you as a treatment option, you may at any time change your mind about whether you want to have it performed should your heart and breathing stop. If your wishes change, you only need to tell your doctor, nurse or other health care team member.

As a substitute-decision maker, once you have made a decision, it can be easy to second guess yourself and to doubt whether you have made the "right" decision. All you can do is examine the situation as fully as possible by considering what you know about the patient's wishes or what you think the patient's wishes would be and then make the best decision you can with the information you have.

Conclusion

It can be very challenging for patients and their families to deal with health care decisions that relate to life and death. We hope this booklet has helped you to understand the terms resuscitation, CPR and DNR and that it has made your circumstance a little easier.

God grant me the serenity to accept

The things I cannot change,

The courage to change the things I can,
and the wisdom to know the difference



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