Advance Directives: A Family Caregiver’s Guide

Advance Directives

Advance Directives are written documents that tell others, especially health care professionals which medical treatments people do or do not want. These may include the use of a ventilator (breathing machine), artificial feeding (tube through the stomach), and other types of medical treatments. Advance directives become effective only when the person cannot speak for him- or her-self. This may be because the person is too ill or mentally unable to make decisions. Advance directives cover two basic kinds of information:

1. The kinds of treatments that your family member does or does not want.

2. Who will be the person who can make health care decisions if your family member is unable to do so.
Here are the most common forms of advance directives:

- **Health Care Proxy.** A form that allows a person to name someone else—called a health care agent or a surrogate (substitute)—to make health care decisions on his or her behalf. This is done by completing a Health Care Proxy form. Each state has its own laws and regulations regarding surrogate decision makers. You can contact your state’s Department of Health to find out the laws and forms that apply in your state.

- **Living will.** A written description of what kind of medical treatments a person would or would not want in the future. The living will and written instructions on the Health Care Proxy form have similar goals, but the State-approved form is likely to carry more weight with health care professionals.

- **Do Not Resuscitate (DNR) order.** DNR allows a person to make a health care choice about one specific treatment. It is used when people stop breathing or their heart stops. The DNR tells the health care team that the patient does not want cardiopulmonary resuscitation (also called “CPR”) which means trying to restart the heart beat. Here are some facts to know about the DNR:
  - The DNR order must be signed by a doctor.
  - As a family caregiver, you may also be asked to sign the order.
  - The DNR is valid even if there is no health care proxy.
  - If a DNR order was signed in one facility, for example a hospital, it does not automatically mean it will be valid in another. You need to find out whether a new DNR order needs to be signed or if the existing order can be transferred and how.
Now is a good time for your family member to complete the Health Care Proxy if he or she does not already have one. As the family caregiver, it is also a good time to complete your own Health Care Proxy. Doing this can help ensure that your medical choices are respected and followed.

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- There is a special type of DNR to be used at home, called an Out-of-Hospital DNR Order. This tells emergency personnel not to perform CPR if your family member’s heart stops when at home. The Out-of-Hospital DNR Order must be signed by a doctor.

- Several states have POLST (Physician Orders for Life-Sustaining Treatment) forms that allow for DNR and other orders to be followed when patients are transferred from one health care setting to another. In New York State, the document is called MOLST (Medical Orders for Life-Sustaining Treatment).

Talking About Advance Directives

It can be very hard to think about a time when your family member will need a health care proxy (a time when he or she will not be able to make decisions). It is also hard, or impossible, to predict what types of decisions will need to be made. That is why it helps to talk now about your family member’s health care choices. This is a comfort and guide for all involved.

Sometimes the hardest part of this conversation is getting started. You can stress that it is important that you know what your family member wants so that you can speak for him or her if it becomes necessary. Ask your family member’s social worker or other health professional if you want help talking about advance directives.

Notes and Questions