

Guide for Pennsylvania Health Care Agents

If you are in a position to make medical decisions for someone else, this guide is for you. If you have been named in someone's health care power of attorney or other advance directive, then you are referred to as the person's *Agent*. Even if you have not been named, you may be called upon to participate in medical decisions for close family or friends who are in a medical crisis and cannot speak for themselves.

EXACTLY WHAT ARE YOUR DUTIES AS AGENT?

Your duties depend on what the person's advance directive says and upon Pennsylvania law. You have to read the advance directive. Pennsylvania's law is found in Act 169 of 2006. Your duties begin when the individual loses the ability to make health care decisions on his or her own.

In general, you will have authority to make any and all decisions a patient would make for him or herself, if able. This includes:

1. Receiving the same medical information the individual would receive.
2. Conferring with the medical team.
3. Reviewing the medical chart.
4. Asking questions and getting explanations.
5. Discussing treatment options.
6. Requesting consultations and second opinions.
7. Consenting to or refusing medical tests or treatments, including life-sustaining treatment.
8. Authorizing a transfer to another physician or institution, including another type of facility (such as a hospital or skilled nursing home).
9. Special rules may apply to withholding or withdrawing life-sustaining nutrition and hydration or if the individual is pregnant.

HOW TO MAKE MEDICAL DECISIONS

The toughest decision may concern beginning or stopping life-sustaining treatments. In each life there may come a time when the patient's condition has deteriorated and it is clear that he or she will not get better. Family members or doctors may then question the value of life-sustaining treatments that seem to prolong the process of dying. Rather than thinking of this as depriving your loved one of necessary treatment, you may be protecting him or her from unnecessary pain and suffering. Many people say they do not want to die slowly, hooked up to machines or fed artificially through tubes. What does your loved one think? Use the steps on the next page to help you decide.

STEPS FOR AN AGENT TO FOLLOW

Deciding for a loved one (whom we will call Mary)

1. **Find out the medical facts.** This requires talking to the doctors and getting a complete picture of the situation. Questions you can use:
 - ▶ What is the name of Mary's condition?
 - ▶ If you don't know exactly what's wrong, what are the possibilities?
 - ▶ Are tests needed to know more? Will the outcome of more testing make any difference in how you treat her, or in how she wants to be treated? (If not, why do the test?)
 - ▶ What is the purpose of each test? Do these tests have risks associated with them?
 - ▶ Is the information you need worth the risk of the test?
 - ▶ What is her condition doing to her now?
 - ▶ How do you explain her symptoms?
 - ▶ What usually happens with this disease?
 - ▶ What do you think now will be the likely course of this disease or condition?
 - ▶ How severe or advanced is her case?

2. **Find out the options.** Make sure the physician describes the risks and benefits of each option. You may want to ask:
 - ▶ How will this option make Mary improve or feel better?
 - ▶ What is the success rate statistically? What is success?
 - ▶ Can this procedure be done on a trial basis and then reevaluated? What is an appropriate amount of time for a trial? Are you willing to stop it after an agreed-upon trial?
 - ▶ What defines "success" for this option? (It may not be what Mary would consider a success.)
 - ▶ What will it mean to her quality of life?
 - ▶ If she is to die, how might it affect the circumstances of her death? (For example, will it likely require hospitalization instead of home care?)
 - ▶ What are the possible side effects?
 - ▶ What option do you recommend, and why?

3. **Figure out how Mary would decide if she knew all the facts and options.** You have three possible approaches to making the decision:
 - ▶ One - If you know Mary's preferences, follow them.
 - ▶ Two - If you do not know Mary's wishes for the specific decision at hand, but you have evidence of what she might want, you can try to figure out how she would decide. This is called *substituted judgment*, and it requires you imagining yourself in the patient's position. Consider her values, religious beliefs, past decisions, and past statements she has made. The aim is to choose as Mary would probably choose, ***even if it is not what you would choose for yourself.***
 - ▶ Three - If you have very little or no knowledge of what Mary would want, then you and the doctors will have to make a decision based on what a reasonable person in the same situation would decide. This is called making decisions in the patient's *best interest*. Evaluate the benefits and burdens of the proposed treatment. For example, will the treatment cause Mary pain or suffering? Is it likely to make Mary better?

THINGS AN AGENT CAN DO TO MAKE DECISIONS EASIER ...

DO prepare in advance with the individual. Learn what is important to your loved one in making health care decisions. Do this before he or she loses the ability to decide. Talk about beliefs and values regarding living, and dying. Talk about spiritual beliefs.

DO make yourself and your role known to the medical staff. Make sure the advance directive is in the medical chart. Keep a copy yourself, handy, to show to people involved in the individual's medical care. Keep in touch with these people.

DO stay informed about the person's condition as it changes. Medical conditions change. Staff at the hospital change. Identify the person who can best keep you informed of the individual's condition. Stay involved and be flexible.

DO keep the family informed, if appropriate. You may have the legal authority to make medical decisions even if family members disagree. However most proxies are more comfortable if there is agreement among loved ones. Good communication can foster consensus. But you may also need help in resolving family disagreements. Ask for the facility's patient representative or ombudsman, social worker, clergy or spiritual advisor. Or ask for the ethics committee or ethics consultant.

DO advocate on the patient's behalf and assert yourself with the medical team, if necessary. Some medical people may not be as comfortable as others with your involvement. You may disagree with the doctor's recommendations. It is hard to disagree with medical professionals and institutional authorities. Be tactful and assertive. If their resistance becomes a problem, or if you feel you are not being heard, ask for help. Ask for help from the facility's patient representative or ombudsman, social worker, clergy or spiritual advisor, ethics committee or ethics consultant.

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Marshall, Parker & Associates, LLC

Jersey Shore, Williamsport, Wilkes-Barre, Clarks Summit
1-800-401-4552
www.paelderlaw.com

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