

Health Care Decisions

Protect Yourself – Plan Ahead



This booklet is about the ways you can protect your right to make your own decisions about your health care. It is not just for people who are very ill; it is for everyone. Many cancer patients are “healthy” except for the cancer. Many will be cured of their cancer. Making decisions about your health care is important no matter how well or healthy you are.

Often, illness can come on suddenly. As long as you are awake and can communicate, your doctor will discuss any decisions that need to be made with you. You will decide together what choice is best for you. However, a time might come when you cannot communicate. Thinking ahead about the choices you and your doctor might face will help you plan for the kind of care you want.

Why is planning ahead so important? Won't my doctor know what is best for me?

Without knowing your wishes, your doctor will do what he thinks best, but that might not be what you would want. Planning ahead gives you control. It is important if you know what you do or do not want at the end of your life.

Planning ahead requires you to think about what you want. For example, suppose you were nearing the end of your life and your heart stopped beating. Would you want your heart to be restarted? You might imagine the answer to be “yes, I would want to live as long as I can.”

- But what if restarting your heart would mean you would be on a breathing machine for the rest of your life?
- What if you would never wake up?
- What if you would still die within days or weeks?

Then the answer to the question might be “no, I would not want my heart restarted.” On the other hand, what if you were told you had about six months to live, but you were still active. Imagine that you had a heart attack. In that case, if doctors were able to restart your heart, perhaps you would return to life as it was. Then your answer might be, “Yes. I want you to try to restart my heart if I have a good chance of going back to being the way I was.” As you think about the answers to these questions, you are beginning to plan ahead.



Another reason to plan ahead is that you might have strong feelings about how and where you die. You might want to die at home. Or, you might want to be in the hospital with doctors and nurses to care for you. You might or might not want to be in a nursing home. Some of these choices are personal; others have to do with cost. Perhaps your insurance would cover the cost of being in the hospital but not home health aids. Perhaps a relative had a wonderful experience in hospice or a nursing home. If your family, your health care agent, and your doctor know what you want, they can do their best to help you have the kind of death you want. By letting them know ahead of time, they also won't be faced with having to make a decision if you can't communicate. Often family members worry that they are not doing what their loved one would have wanted. Telling them before a decision needs to be made makes everyone more comfortable. It can give them a sense of peace in carrying out your wishes.

Deciding for Yourself

The ideal way to plan for your future health care is to talk to your doctor while you are healthy. You might want to talk to your general medical doctor. You should also talk to your cancer doctor. Let your doctor know what you do or do not want to happen to you if you cannot speak for yourself. This may be near the end of your life, but not necessarily. You may simply be too sick to speak at a given moment. For example, you might say, "Please do not keep me alive if I can no longer have a meaningful life." This gives you and your doctor the chance to talk about what you mean by "meaningful." Having this talk gives your doctor the chance to explore your feelings and to ask specific questions. It also makes your doctor your active partner in fulfilling your wishes. At the end of your discussion, your doctor will note your wishes in your medical chart.



While this is an important conversation, it may not be enough.

Another way to protect yourself is to appoint a health care agent. We ask all of our patients to do this, even if they are here only to have tests. Your health care agent can only speak for you if you cannot speak for yourself. Be sure to tell your agent what kind of care you do or do not want. Then, if a time comes when you cannot speak for yourself, your agent will know your wishes. For more information about appointing a health care agent, ask for the card "What You Need to Know about a Health Care Agent." The form you complete to assign a health care agent is called the proxy form. Your doctor, nurse, social worker, and patient representative can all tell you how to get a health care proxy form. They can also tell you more about how to appoint a health care agent.



Why is it so important to have a health care agent?

There may come a time when you cannot communicate. If health care decisions come up, your agent will speak for you. If you do not have an agent, your family will be asked to speak for you. If they know your wishes, they might make the same decision you and your agent would. But sometimes, family members disagree. A wife might want one thing, while a parent wants a different one. It is better to let your doctor and your agent know what kind of care you want.

The experiences of others may help you think about the kinds of things that you would want your doctors to know.



“...we’ve been married for over 50 years. We’ve talked about everything in 50 years, but we never talked about what we’d want at the end of our lives. Whenever one of us got sick, we always got over it. This time he’s not going to ‘get over it’ and he’s not able to tell me what he wants. I don’t know what to do for him. I feel like a bad wife!”

“When I was in the hospital for surgery, my husband asked me what I would want if my heart stopped or something. I said, “Whatever was available! I’d want to live! Make them do everything for me!” But he never said what he would want and now he’s the one on a ventilator and he can’t tell me. I believed he felt the same way I did, but I don’t really know for sure. Now I’m watching him suffer and they tell me he can’t get better. Knowing what I know now, I would answer his question in a different way. I would never want to be in the place he’s in – but I am stuck with the fact that he seemed to agree with me. I am trying to respect what I think were his wishes, but it gets harder every day. I wish we had talked about this with someone who could have helped us think this through better. I am definitely going to talk with my doctor and my children now!”

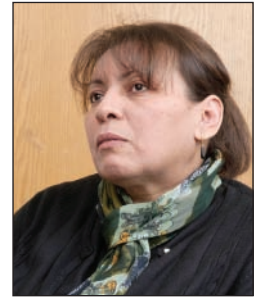


“It’s so hard to hear the words, “There’s nothing more we can do that would cure his cancer.” My father has had cancer three times. The first two times he was cured. I expected it to happen again. Now he’s in and out of awareness and can’t really tell me what he wants. We’ve never talked about this. My mother has dementia, so she can’t help. I want to do the right thing for him, but I also want to be sure my sisters know I did everything I could. Now, while I should be enjoying every minute with him, I’m paralyzed with worry.”

“If I can’t take care of myself or feed myself or sing in the choir – what’s the point? I’ve been independent all my life, even as a baby. I can’t imagine being stuck in my bed or a wheelchair, unable to walk or eat by myself or toss the ball with my grandsons. But as strong as I feel about this, it’s hard to talk about with my family. They think I can handle anything – no matter how painful, no matter how much I might hate it. But having to depend on others – even them – for everything is a kind of pain I can’t handle. I simply don’t have the right words to tell them to let me go when the time comes! I need help.”



“Helen and I have been best friends since high school. When we both became widows within a few months of each other, we decided to pool our resources and share expenses. The two of us bought a house, divided the costs and have enjoyed both friendship and a great deal of independence for the last twelve years. Now, she’s in a coma and I am here, helpless. We talked about this possibility – what would happen if one of us got sick. We even went to a lawyer and had him help us figure out how to divide our property legally in order to protect each other’s interests in the event that one of us should die unexpectedly. But we never did anything about giving each other permission to make healthcare decisions. What were we thinking! I really do know her wishes but don’t have any authority to help make decisions. Her son seldom visited her at our house. He was busy with his own family out in California and when they talked on the phone, it was all small talk, nothing deep. Now he’s trying to make up for lost time I guess, and he isn’t interested in anything I have to say. Maybe he feels guilty because I knew her better than he did; maybe he just isn’t ready to let go. I understand that. But either way, she did not want to be like this – hooked up to machines with no hope of getting better. I know that, but can’t do anything to help. I feel like I’ve let my friend down after all these years of our taking good care of each other! And someday her son is going to realize what he has done and maybe feel even worse than he already does. This is so sad! I’m certainly going to make some clear arrangements for myself!”



What do I need to tell my health care agent?

You might start a conversation by talking about your values and philosophy. Let your agent know what is important to you and what would make living meaningful. For example:

- What makes your life worth living?
- How important is it for you to be independent?
- What if your brain was no longer functional?
- What if you were on a respirator with very little hope of recovery?

You might then switch the conversation to specifics. Tell you agent how you feel about:

- Cardiopulmonary resuscitation (CPR). This is what is done if your heart stops beating or you stop breathing. Pressure is used on your chest to try and restart your heart. A breathing tube is put in your airway and a machine makes your lungs breathe. You will need to decide in what situations you would want CPR performed. For example, would you want CPR if you are active and feeling well, but suddenly had a heart attack? Would you want CPR if you were dying of cancer?
- Intubation and mechanical ventilation. Intubation means having a tube that goes through your mouth and into your airways. Mechanical ventilation is when a machine is attached to the tube to send air into your lungs. It is used during operations. In this case, it is removed as soon as you wake up. It is also used when you can no longer breathe on your own. In this case, you may not ever breathe on your own again.
- Artificial hydration and nutrition. Artificial hydration is getting fluid through a vein. Artificial nutrition is liquid formula that has the nutrients your body needs. It can be used to get you through a treatment that might help you recover. It could also be used to keep your body alive even if there was very little chance you could recover.
- The benefits or burdens of treatment. For example, antibiotics might make you more comfortable. However, taking them can also prolong your dying.

These are not easy things to think about. But you and your agent may be glad you did. These discussions will help both of you think more deeply about what you want. Telling your agent what you want does not mean you cannot change your mind later. That is an important reason to have ongoing talks with your agent. You may change your mind many

times depending on your health. If you have put your wishes on your health care proxy form, you can change it at any time. Simply destroy all copies of the old form and write a new one. Give copies of the new form to your doctors and your agent. Or, if you are sure that your agent would make the same decision you would, do not write anything on the form.

And remember, your agent can only speak for you if you cannot do so yourself.

What does DNR mean?

DNR stands for Do Not Resuscitate. It allows you to have a natural death. In fact, some states now use AND instead of DNR. AND stands for Allow Natural Death. It means no one could pound on your chest to try to restart your heart if it stopped beating. No one could use electric shock to try to restart your heart. No one could put medicine in your veins to try to restart your heart. No one could put in a breathing tube and connect you to a breathing machine. Allowing a natural death means letting “nature take its course.”

The doctor must discuss a DNR order with you, your agent, or your designated decision-maker before writing it. The order can only be written after you agree to it.

- A DNR for patients who are at home is called a non-hospital DNR order. Your doctor must renew it at least every 90 days. Your primary care doctor can do this. You must keep this DNR order handy. If your family calls 911 and emergency personnel arrive, they must be shown the DNR. Otherwise, they must start CPR if you have no heartbeat. This is also true if you are in hospice care or visiting nurse care. Make sure your family members, or the people living with you know where to find it.

What is a Living Will?

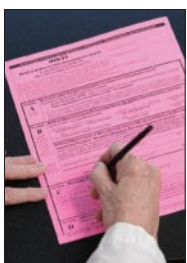
A living will is a legal document. On it, you state your wishes for the care you want at the end of life. A living will is not necessary in New York State. A completed and witnessed health care proxy form is enough. If you do not live in New York, www.caringinfo.org has living will forms for all states. In New York, a living will is used as evidence of your care choices at the end of your life. This is important if you do not have a health care agent.

How can I make sure all doctors will listen to my health care agent or respect my wishes as stated in my living will?

The first step in making sure your doctors follow your wishes is to let them know what your wishes are. Talk to them. Make sure they all have copies of your proxy form or living will or both. Make a copy for each doctor who might care for you. You do not have to bring a copy with you each time you are admitted to a hospital. But it would not hurt if you did. Ask your nurse to make sure it is in your chart.



What is MOLST?



MOLST stands for Medical Orders for Life Sustaining Treatment. It is for people who have a serious condition or who are nearing the end of life. A doctor completes the form after discussing end of life care with you or your agent. Both you and your doctor must sign the form. It has recently been recognized as a legal document in New York State.

The form has boxes to check if you do or do not want a DNR order. It also allows you to choose between three levels of care.

- **Comfort Measures Only** means you would be offered food and drink, but would not get them through a vein. You would get medicine and other measures to relieve pain and any other symptoms. You would get oxygen only if it made you more comfortable.
- **Limited Medical Interventions** lets you pick the specific things you would allow. You could not pick CPR or mechanical ventilation if you have decided on DNR.
- **No Limitations on Medical Interventions** means that doctors can do what they think is needed. The form also allows you to say:
 - When you would want to be hospitalized.
 - Whether you would want antibiotics.
 - Whether you want fluid and nutrition given through a vein or feeding tube.

What is the difference between an advance directive or living will and the MOLST?

One important difference is that you can make a living will when you are healthy and only thinking about some future health state. The MOLST is used for people who have serious, chronic conditions. It is most often completed when death could occur at any time.

Another big difference is that the MOLST cannot be completed unless you and your doctor discuss it. You can complete a living will without ever talking to your doctor. You can complete a health care proxy form without discussing your wishes with your doctor.



How can I make sure my wishes are followed if I can't speak for myself?

- You can make sure your health care agent knows your wishes. Your doctor must have a copy of your health care proxy form that states the name of your agent, is dated, signed by you, and witnessed by two people who are 18 or older.
- You can do two things with your health care proxy form:
 - Insert your directions for care, (e.g., no artificial nutrition, no CPR).
 - Not write in any directions, but trust your agent to make the decisions you would want.
- You can fill out a living will and provide a copy to all of your doctors. This is not necessary in New York. But it would help to provide clear and convincing evidence of your wishes. This might help doctors make decisions about your care if you do not have a health care agent.
- If you know you are nearing the end of your life, you can ask your doctor to complete a MOLST form with you.



Final Thoughts

Death is an ending as surely as birth is a beginning. Your birth was likely a time of great joy for your parents and siblings, but you had no control over it. Your death will cause sadness, but you can have some control over it. For it to be the kind of end you envision, you must plan ahead.

Being prepared gives you and your family control over some important things. The end of a life is sad and the time together is precious. Planning ahead allows you and your family the freedom to enjoy every moment.

Resources

- Caring Connections
www.caringinfo.org
- Compassion and Support
www.compassionandsupport.org
- New York Online Access to Health
<http://www.noah-health.org/en/rights/endoflife/adforms.html>
- New York State Department of Health
www.nyhealth.gov/professionals/patients/health_care_proxy/intro.htm



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