

Making Medical Decisions for Someone Else: A How-To Guide



**The American Bar Association
Commission on Law and Aging**

This guide is based on *Making Medical Decisions for Someone Else: A Maryland Handbook* (2006) by the American Bar Association Commission on Law and Aging in collaboration with the Maryland Office of the Attorney General.

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The ABA also invites the collaboration of interested state groups, such as bar committees, to develop state-specific versions of this *Guide*. Contact the ABA Commission on Law and Aging at abaaging@abanet.org.

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CONTENTS

I.	Who Is This Handbook for?	1
II.	What Is It Like to Be a Health Care Proxy?	2
III.	What Should You Do While There Is Still Time?	4
	Understanding the Patient's Wishes and Values	
IV.	Steps to Follow in Making Medical Decisions	5
	1. Find Out Medical Facts	5
	2. Find Out Options	5
	3. Figure Out How the Patient Would Decide	6
	4. If You Don't Know, Choose What Is in the Patient's Best Interest	6
V.	Working Within the Health Care System	7
	1. What Can You Do?	7
	2. Talking with Doctors	8
	3. Using Advance Directives and Related Documents	9
VI.	Resolving Disputes and Getting Help	10
	1. What If There Is a Disagreement?	10
	2. Resources to Help You	11
	3. Getting More Information	12
VII.	Situations Often Faced by Proxies	13
	1. Experiencing Grief	13
	2. Making Sure Pain and Symptoms Are Well Managed	13
	3. What About Hospice?	14
	4. What to Do in an Emergency	14
	5. What About DNR Orders?	15
	6. What About Surgery?	16
	7. What About Artificial Nutrition and Hydration?	16
	8. What About Medical Research?	17
	Appendix	
	The Proxy Quiz—A Tool for Better Understanding	18

I. Who Is This Handbook for?



If you make health care decisions for someone else—or might at some future point—this handbook is for you.

Bill's mother had a stroke. She was no longer able to talk or understand. In the hospital, a team of doctors and nurses was working to treat her. There were many decisions to be made. The doctors looked to Bill to make the hard choices. Bill was worried and nervous and did not understand everything that was going on. He was afraid his mother was dying. He wasn't sure what she would want in this situation. He didn't know where to turn.

Just as with Bill, when someone close to you is seriously ill, a doctor might ask you “What should we do?” When this happens, you are acting as a **health care proxy**—which is the general term used in this *Guide* for anyone who can make health care decisions for someone else. There are three kinds of proxies:

1. **A health care agent.** Your relative or friend has signed a legal document called an **advance directive** naming you to make health care decisions for him or her in case something happens. Some people call this a *durable power of attorney for health care*. Your state's terminology may differ, but the concept is identical.
2. **A legal surrogate.** Even when nobody has named you as a health care agent, you may still be asked to make medical decisions for someone else. If you are a family member or possibly a close friend, you may be called upon to make decisions as the default decision-maker. In most states, you would be referred to as a **surrogate**, but again, state terminology varies.
3. **A guardian.** A court may appoint you as a **guardian** or **conservator** and specifically authorize you to make health care decisions for someone else. A guardian is directly answerable to the appointing court.

There are three kinds of health care proxies:

Agent, Surrogate & Guardian.
But in all cases a proxy is a person who can make health care decisions for someone else.

The authority of each kind of proxy is a little different, but all share the challenges of health care decision-making for someone else. This handbook tells what it is like to be a health care proxy, what to do while there's still time to think about it, and what to do in a crisis. It also talks about situations that proxies often face and tells where to get help.

II. What Is It Like to Be a Health Care Proxy?



*A long-time friend of the family, who is like an uncle to me, asked me if I would be his health care agent under an advance directive he was planning to sign. I didn't know what to say or think, so I said, "Sure. I would be happy to." But I don't really know what I'm getting myself into. What **am** I getting myself into?*

If you are a health care proxy, you can make decisions and take actions that a patient would make or do, if able. This includes:

- ❖ **Getting the same medical information** the patient would get. You should have access to the patient's medical records and any information you need about the patient's health or health care. If you are having trouble getting the patient's medical information, contact the medical facility's privacy officer and ask for help.
- ❖ **Talking with the medical team** about treatment choices. Ask questions and get explanations, so that you can understand the patient's medical condition and treatment options as much as possible.
- ❖ **Asking for consultations** and second opinions from other doctors.
- ❖ **Consenting to or refusing medical tests or treatments**—including life-sustaining treatment in many, but not all, cases.
- ❖ **Deciding whether to transfer** the patient to another doctor or health care facility (such as a hospital or skilled nursing home).
- ❖ **Getting the doctor and other medical professionals to communicate with the patient** if he or she is still able to understand anything.

Being a proxy can be difficult. But there are several key things to remember:

- **Saying yes or no.** If someone asks you to be a proxy, you don't have to do it. It may be hard enough coping, even without the added responsibilities of making health care decisions. But it is an important way to help someone you care about.

Being a Proxy

As a proxy, you have the special privilege of doing something important for the patient.

- **Anxiety is normal.** It is not unusual to feel lots of emotion, stress, and doubt. And you may not be comfortable around doctors, the medical words they use, and busy hospitals. It is a tough job. But there are many places to go for help, so you are not alone. See Section VI.
- **It's not about your money.** There could be choices about money and insurance, but your own money is not at risk. Being a proxy does not make you owe or pay anything with your money or risk being sued. It is only the patient's money and insurance that is involved.
- **Inaction has consequences, too.** If you are a proxy, you will be expected to make decisions. The doctor is relying on you for guidance, so consult with the medical professionals involved and try to sort out the choices.
- **Keep the patient involved.** Even though the patient is not able to make health care decisions, he or she might still have something helpful to say. If you can communicate with the patient, try to involve him or her in the decisions as much as possible. If the patient is able to express meaningful choices, these should always be sought out and honored.
- **Respect culture.** The patient's cultural background might be one of many factors affecting how health care decisions are made. In some cultural groups, for example, the whole family is involved. But what the individual patient would have wanted is the most important thing.

III. What Should You Do While There Is Still Time?

Understanding the Patient's Wishes and Values



Now that I have become my dear friend's health care agent, is there anything I should be doing now before I'm called on to make decisions?

Your first task is to learn as much as possible about **what the person would want** if he or she were seriously ill. What choices would be in line with the person's personality, religious beliefs, personal values, and past decisions? What fits with the person's "life story"? How would that person want to live the final chapter of life? This is important to learn because the law in most states tells you to try to decide as the patient would, even if the decision goes against the way you would decide for yourself. You must be able to put yourself in the patient's shoes and speak with the patient's voice to the extent possible.

Try to prepare in advance with the person for whom you are a proxy. This means having conversations about what the individual would want **before** a crisis arises. Not everyone can do this, but if there is still time, you will be glad that you did. Learn what is important to the patient in making health care decisions. What is the person hoping for in his or her health treatment?

Don't be afraid to use the "D" word: *Dying*. It's hard to talk about illness and dying, but it's a lot harder making decisions without having a sense of what the person would want.

Tips:

- One way to begin the discussion is to **tell stories**. Ask the person about his or her past life, what was meaningful, what happened when others in the family were ill—anything to draw out values and beliefs.
- Another way you can get the conversation going is by using the **Proxy Quiz** in the Appendix of this guide. The quiz will help you find out how well you know the health care wishes and values of the person for whom you are a proxy. It will help start a conversation and might result in better mutual understanding.

Telling stories can be a way to find out about the patient's wishes and values.

IV. Steps to Follow in Making Medical Decisions



Carla stood in the hospital hallway with the doctor who was explaining the seriousness of her mother's condition. Some time ago, her mother had named Carla as her health care agent in her advance directive. But Carla is still in shock over what is happening. And she is now being asked to make some very important decisions about her mother. How does she begin?

Once a crisis occurs, it often is easier if you have talked with the patient in advance, as suggested above. But whether you had such a conversation or not, you can use these basic steps to help you make decisions on the patient's behalf.

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 the patient'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 the patient, or in how the patient wants to be treated? (If not, why do the test?)
- ▶ What is the purpose of each test? Do these tests have risks?
- ▶ Is the information you need worth the risk of the test?
- ▶ How do you explain the symptoms?
- ▶ How severe or advanced is this case?
- ▶ What do you think will be the likely course of this disease or condition?

2. Find out the options. Make sure the doctor describes the risks and benefits of each option. In comparing these options, ask:

- ▶ How will this option make the patient improve or feel better?

Steps in Making Medical Decisions

- Find out the facts.
- Find out the options.
- Decide based on
 - what the patient would do, or
 - what's best for the patient.

- ▶ Can this procedure be done on a trial basis first? What is a reasonable amount of time for a trial? Is the doctor willing to stop it after an agreed-upon trial?
- ▶ What defines “success” for this option? (It may not be what the patient would consider a success.) What is the success rate for people like the patient?
- ▶ What will it mean about the patient’s ability to do things and to communicate meaningfully with family and friends?
- ▶ If the patient is to die, how might it affect the circumstances of death? (For example, will it likely require hospitalization instead of home care?)
- ▶ What are the possible side effects?
- ▶ What option does the doctor recommend, and why?

3. Figure out how the patient would decide if he or she could.

- ▶ If you know what the patient would want, most states laws law say you should act on it. If the patient left written instructions, do your best to follow them.
- ▶ If you do not know the patient’s wishes for the specific decision at hand, you still might have a solid basis for figuring out how he or she would decide. Consider the patient’s values, religious beliefs, past decisions, and past statements.

What would the patient want?
 The aim is to choose as the patient would probably choose, ***even if it is not what you would choose for yourself.***

4. **If you just don’t know what the patient would do, choose the option that is in the patient’s best interest.** If you have little or no information on what the patient would want, then your job under the law is to do what you believe to be ***best for the patient.*** In weighing the options, you should consider what a reasonable person in the same situation would decide. Don’t be influenced by whether the patient is poor or has a long-term disability.

V. Working Within the Health Care System



Ellen's mother was undergoing treatment in a hospital. Ellen had never spent time in a hospital before and it seemed confusing. While the medical staff was working hard as a team, the same staff was not there all the time. Their schedules shifted depending on the time of day and the day of the week. Her mother had several doctors, including a general practitioner and specialists in certain areas. And each of these doctors had many other patients, so they had limited time for Ellen. And besides, just being in a hospital where many people were ill was stressful.

Being suddenly thrust into the hospital or other medical setting may seem like visiting a foreign land. Even for people familiar with the routines of the system, it can be challenging. However, here are some tips that can help you do a good job as a proxy for a loved one or friend.

1. WHAT CAN YOU DO?

- **Make yourself and your role known to the medical staff.** Make sure any advance directive is in the medical chart and medical staff know what it says. Have a copy ready to show to people involved in the patient's care. Keep in touch with these people.
- **Stay informed about the person's condition.** Medical conditions change. Find the person who can best keep you informed of the patient's overall condition. Stay involved and be flexible. Read the medical record often. Keep a written log of medication and treatment changes.
 - Be Visible
 - Be Informed
 - Be Involved
 - Be Heard
- **Be ready for transfers to another medical setting.** If the patient is moved from one section of the hospital to another or to a different facility, make sure that you know the treatments to be continued or begun after the transfer. Meet with the new medical team or head nurse to be sure that they are aware of the ordered treatment.
- **Advocate on the patient's behalf and assert yourself with the medical team, if necessary.** If you are confused by the doctor's recommendations, don't stay quiet. Be tactful, but insist that medical issues be explained to you in words you can

understand. If you feel you are not being heard, ask for help from the places listed in Part VI. Be a squeaky wheel, if need be.

- **Ask for a second opinion, if necessary.** If you disagree with the doctor or if you are just not sure what to do, get an opinion from another doctor. If need be, you have the right to transfer the patient to another doctor or facility.
- **Consider a time-limited trial** for some treatments. Sometimes it is difficult to weigh the benefits and problems of a treatment. Trying a treatment for a certain period of time may show if it improves the patient's situation. Be sure that the time limit is clear before beginning the treatment.
- **Consider hiring a private care manager** if you are unable to work with the medical team on your own. A care manager, who usually has an advanced nursing or social work degree, can help you understand the medical situation and advise on care options.

2. TALKING WITH DOCTORS

You will have limited time with the patient's doctors, so prepare in advance to get the most out of the each visit.

- **Make a list of questions** to ask the doctor, such as concerns about symptoms, changes that have occurred, or medication reactions.

Prepare well
for the time
you have with
the doctor.

- **Present your points or key questions right away.** Ask the doctor how much time he or she has, and begin with the most important problem first. If you know what you would like done, say so at the beginning. If you have questions, ask the most important ones first.
- **Have a list of all medications** the patient is taking, including vitamins and supplements. Sometimes if there are several doctors involved, each one may not know about all the medications. This is important since medications can interact with each other.
- **Don't hesitate to ask questions** about what the doctor says. For example, ask: What will this treatment do? What would happen without the treatment? What are the side effects? How long will it take? Is it covered by insurance? What if the patient has a reaction to the treatment later? Make sure you understand. It may help to repeat what the doctor told you in your own words, to be sure there are no misunderstandings.
- **Take notes** to help you remember what the doctor says.
- **Consider bringing a friend or relative** of the patient's with you to help you remember what to ask and what the doctor says—and for moral support!

3. USING ADVANCE DIRECTIVES AND RELATED DOCUMENTS

If the patient has a Durable Power of Attorney for Health Care or a Living Will or other form of Advance Directive....

- Be aware of exactly what it says because it should give you guidance on how to exercise your authority as a health care agent.
- Make sure the treating health care professionals and health care facility are aware of it and have a copy.
- If instructions in the document are vague (and this is actually quite common), you may have to make the best judgment you can with the information you have. Consider prior discussions the individual had with you or others that may shed light on their wishes and values. You may also find it helpful to discuss this with the patient's treating health care providers.

In many states, there are other helpful documents to be aware of and to use if appropriate:

- Out-of-Hospital Do-not-resuscitate (DNR) orders are available in most states and are very important for seriously ill individuals living in the community who, under their current condition, do not want resuscitation by emergency medical services or EMS personnel if their breathing or circulation stops. See **“What About DNR Orders”** on page 15.
- POLST Form (Physician's Orders for Life-Sustaining Treatment). A growing number of states have adopted some version of this medical order, also called by other names such as MOLST (Medical Orders for Life-Sustaining Treatment) or POST (Physician Orders for Scope of Treatment).

POLST expands upon the out-of-hospital DNR order by including additional instructions in the form of a medical order about the level of medical care versus comfort care desired, including whether to hospitalize; the use of artificial nutrition and hydration; and possibly antibiotic and ventilator use.

VI. Resolving Disputes and Getting Help



Trish visited her father every day in the nursing home. She knew he was having a harder and harder time eating, even though the nursing home staff spent considerable time assisting in feeding him everyday. His doctor said that he could be fed by a tube into his stomach, but she thought her father would not want that. Her brother and sister both wanted to start the tube feeding, and Trish felt pressured.

As a proxy, you are probably not operating alone. You may be part of a family or network of friends who are grieving about the medical condition of the patient and under stress because of the medical crisis. Emotions may run high. You must make decisions that others may or may not agree with. The decisions you make may weigh on your mind in the future. You may have to defend your decisions against family members. And long-standing family dynamics can be exaggerated in a situation like this. In addition, you or your family may disagree with what the doctor advises.

1. WHAT TO DO IF THERE IS A DISAGREEMENT

- **Understand your legal authority.** Under the law in most states, certain family members and others have priority in making health care decisions for the patient. The following order of priority is commonly used:
 - Anyone named by the patient in an advance directive
 - Any guardian appointed by the court
 - The spouse
 - An adult child
 - Parent
 - Adult brother or sister
 - Certain friends or other relatives.
- **Ask for an ethics committee meeting if necessary.** If people with equal priority for decision making disagree, the case can be referred to a hospital or nursing home **ethics committee**. These committees deal with ethical issues, such as end-of-life decision-making. They help to educate the staff and to sort out difficult problems. They usually don't actually make decisions, but advise. They may help proxies, families, or medical staff to better understand each others' views and to explore choices.

- **Keep the family informed, if appropriate.** You may have the legal authority to make medical decisions even if other family members with less priority under the law disagree. However, most proxies are more comfortable if there is agreement among family members. Good communication can help bring about agreement.
- **Use key communication tools.** If family members disagree, make sure you are not talking past each other and that you have the same understanding of the medical facts.
 - Listen carefully to what others have to say.
 - Respect their points of view.
 - Try to understand why they are taking positions different than yours. Repeat back their position to make sure you understand it.
 - Think about what past events or attitudes might be causing them to take such a position.
 - Remember that you are seeking to stand in the shoes of the patient and to advocate the patient’s preferences and values, if you know them, rather than your own.
- **Ask for a care-planning meeting if that might be helpful.** If the patient is in a nursing home, there will be an overall **care plan** that must be reviewed regularly or when changes occur. The care plan covers the key things about the person’s care by the nursing home staff. You can request a care-planning meeting to discuss what the plan is, whether it is really being carried out, and how well it is meeting the person’s needs. If you go to a care-planning meeting, prepare as much as you can beforehand. Come with examples of any problems. Consider having someone come with you to support your concerns.

2. RESOURCES TO HELP YOU

You may need help in serving as a health care proxy or resolving disagreements with family or medical staff. Of course, family members may be your biggest help. But there are also other sources of help:

Look for Resources.
Proxies often need to look to others for help in tough situations.

- **Hospital patient representative or ombudsman.** Many hospitals have patient representatives or ombudsmen to help patients exercise their rights and to be an advocate for patients in the health care system. They try to resolve patient complaints and cut through hospital “red tape.” They try to make sure the voice of the patient—or the proxy—will be heard.
- **Long-term care social worker.** Nursing homes and assisted living facilities may have an in-house social worker to help residents and families meet their needs.

- **Long-term care resident and family councils.** Residents and family members have the right to organize advisory councils in nursing homes, and sometimes these councils exist in assisted living, as well. If your problem is one shared by other residents—such as not enough attention from nursing assistants, frequent pressure sores, unhealthy conditions, or poor food—joining with others in such councils can be very helpful.
- **Long-term care ombudsman.** Under federal law, every state and many local areas have a long-term care ombudsman program. Ombudsmen are independent staff or volunteers in a nursing home or in assisted living. They are advocates for residents in long-term care. They can be very helpful in resolving complaints, mediating problems, or helping the patient and the proxy talk with the medical team or institution. To find the long-term care ombudsman program nearest the resident, see the Web site of the National Long-Term Care Ombudsman Resource Center at: http://theconsumervoice.org/get_help.
- **Clergy or spiritual advisor.** If you are part of a faith community, now is the time to call on your clergy for confidential advice, reassurance, help with the grieving process, help in sorting out differences with others, and help in understanding your own reactions in light of your spiritual beliefs and those of the patient. But remember that in making decisions it is the religious or spiritual beliefs of the patient that matter, not your own.
- **Institutional ethics committee or ethics consultant.** These valuable resources were described earlier.
- The **National Hospice and Palliative Care Organization** provides numerous informational resources online at: www.caringinfo.org.

3. GETTING MORE INFORMATION ON THE LAW

As a proxy, you may have many more questions. Law-related information about health care advance directives, guardianship, deciding for others, and related issues. See the Web site of the ABA Commission on Law and Aging at www.abanet.org/aging, as well as www.ABALawInfo.org.

State-specific advance directives forms may be found on the Web site of the National Hospice and Palliative Care Organization at: www.caringinfo.org/AdvanceDirectives

VII. Situations Often Faced by Proxies

The following tips are about some special challenges you may have in making medical decisions as a proxy.

1. EXPERIENCING GRIEF

When a loved one is dying, it is normal to have thoughts about how you will react and cope after that person's death. You may experience painful visions of life without that person and anticipate feelings of terrible grief and mourning, while at the same time being expected to act as the patient's decision-maker.

You are not alone. These reactions are normal. Sometimes they include feelings of depression, fear, or focusing excessively on particular concerns about the dying person or particular tasks. This process of **anticipatory grief** is a natural part of adjusting to the reality of the loss. It is also a time, if possible, to complete unfinished business with the dying person—for example, saying “good-bye,” “I love you,” or “I forgive you.” Not everyone experiences anticipatory grief. Even if you do, the feelings of grief and bereavement following the death may be much different from what you felt beforehand.

You may also feel guilty after the person dies, asking yourself repeatedly “Did I make the right decisions?” For help in coping with grief or guilt, look for hospice and social work resources or specialized grief and bereavement support groups or counseling.

2. MAKING SURE PAIN AND SYMPTOMS ARE WELL MANAGED

You may need to help the patient get pain relief. Pain can be controlled. It does not have to be a part of being seriously ill.

Talk to the patient to find out as much as you can about the pain. If the patient cannot talk, try to observe the patient's reactions. Try to determine:

- Where is the pain?
- When did it start?
- Does it come and go? When?
- How intense is the pain?
- Is it getting better or worse?
- How does it affect sleep or daily activities?

Talk to the doctor about the pain. Be sure to know what medications the patient is taking. If the doctor can't help, you can ask for a referral to a pain specialist or a pain clinic. Here are 10 questions to ask the doctor:

1. What is causing the pain?
2. What is the plan for treating the pain?
3. What are the benefits of the treatment?
4. What might be the side effects? How long will they last? How will they be treated?
5. What should I watch for and call you about?
6. What should I do if the pain gets worse?
7. When will you check again and see how the patient is responding to the treatment?
8. What is the cost of the pain medication and is it covered by insurance?
9. Is there a lower-cost medication?
10. Are there other ways the pain could be treated?

3. WHAT ABOUT HOSPICE?

For any patient who may be dying, consider hospice care. Hospice is a program that uses a team for medical care, pain management, personal care, and emotional and spiritual support to meet the patient's needs and wishes. Hospice also helps the family caregivers.

Hospice staff is on-call 24 hours a day, seven days a week. They focus on supportive care, comfort, and pain relief, and they may provide needed drugs, medical supplies, and equipment. Additional services are available when needed—such as respite care, speech and physical therapy, or in-patient care. In most cases, hospice is provided in the patient's home, but hospice care can also be given in freestanding centers, hospitals, nursing homes, and other long-term care facilities.

Hospice care is paid for under Medicare, by Medicaid in some states, and most private insurance plans and managed care plans. Families and doctors often wait too long before they consider using hospice. If the patient has a serious and eventually fatal condition, find out when and how hospice could help. For more information, call the toll-free HelpLine of the National Hospice and Palliative Care Organization at (800) 658-8898 or visit their Web site at www.nhpco.org.

4. WHAT TO DO IN AN EMERGENCY

What should you do if the patient is with you at home and takes a turn for the worse? If the patient is in a hospice program, you probably will get special instructions to call hospice staff rather than 911. Otherwise, **call 911** if any of these signs are present:

- Fainting
- Chest or abdominal pain or pressure
- Sudden dizziness, weakness, or change in vision
- Unusual difficulty breathing
- Severe or frequent vomiting

- Coughing up or vomiting blood
- Bleeding that won't stop

When you call 911, speak clearly and briefly describe the problem. Stay on the line until the dispatcher says you can hang up. If someone else is with you, have the other person stand at the street to direct the ambulance crew. At night, make sure the outside lights are on.

Have **key documents** close at hand. This includes any of the patient's medical records that are available, like a copy of an EKG, and any advance directive. If the patient has an EMS/DNR order or your state's version of POLST (see next section), have it ready for the ambulance crew so that they know whether to treat aggressively or to focus only on comfort care.

5. WHAT ABOUT DNR ORDERS?

Cardiopulmonary resuscitation or CPR is a procedure used when a person's heart or breathing stops. People are trained to start the breathing again by applying a lot of force to the chest and breathing into the patient's mouth. The patient will then be put on a breathing machine (sometimes called a **respirator** or **ventilator**) and given strong medication. If the patient is not in a hospital, an emergency medical services team will begin or continue CPR and transport the patient to the hospital emergency room.

CPR and respirators save many lives and this is usually what people want in an emergency. Yet when a patient is seriously chronically ill and death is expected, it may not do much good and can leave the patient far worse than before the CPR.

Some seriously ill people choose not to have CPR used, while others want everything possible done to try to keep their heart and lungs going—no matter what their medical condition. On admission to a hospital or nursing home, it is assumed that every patient whose heart or breathing stops wants CPR. If a patient does not want CPR, a doctor must write an order called a **No Code** or **DNR** (Do Not Resuscitate). If a patient is not in a hospital, the doctor must write an **EMS/DNR** order that tells the Emergency Medical Services (EMS) team not to use CPR and related procedures. Some states use the more comprehensive alternative called **Physicians Orders for Life-Sustaining Treatment** or **POLST** as discussed on page 9.

As a proxy, you may have to make the difficult decision of whether the patient should have a DNR order.

- Talk with the doctor about the likely outcome of CPR for the patient.
- Ask about side effects, and pain or discomfort associated with the procedure. For example, respirators can make it hard to swallow or speak.
- See if there is anything in the patient's advance directive about CPR when the patient is seriously ill, or try to figure out what the patient would want.

Make sure that the medical staff do not interpret DNR or No Code to mean no treatment at all. You still may want the patient to have treatment for other conditions, as well as **comfort care**.

6. WHAT ABOUT SURGERY?

Sometimes a proxy is asked to consent to surgery that a doctor recommends. Here are a few tips:

- Ask why the surgery is necessary, what would likely happen without it, and what the risks are, especially given the patient's age and condition.
- Ask the surgeon how many times he or she has performed the operation, and the outcomes.
- Find out how long recuperation will take and what the patient will have to do to recover.
- At least a day or two before the operation, get all the forms that you will be asked to sign. Read them carefully, and ask about anything that's not clear.

7. WHAT ABOUT ARTIFICIAL NUTRITION AND HYDRATION?

Health care professionals must always make reasonable efforts to help a patient eat and drink normally. But when a patient can no longer take fluid or food by mouth, a **feeding tube** can be used. There are two types of tubes. A **nasogastric tube** is put through the nose, down the throat, and into the stomach. This usually is used on a short-term basis. For a longer term, a **gastrostomy tube** is put by surgery through the skin into the stomach or intestines. For fluids only, intravenous (IV) lines may be placed into the veins of the arm or hand to give artificial hydration.

Feeding tubes help many patients to get the fluids and nutrition they need. They are a lifesaver. Yet, there are some cases where the benefits of feeding tubes may be unclear for a seriously ill and dying patient. Some people say that no matter what the chance of recovery, a feeding tube should always be used unless the patient refuses. Yet, sometimes, artificial feeding and fluids for a seriously ill person can be more of a burden than a benefit.

As a proxy, you may have to make the difficult decision of whether the patient should have artificial nutrition and hydration.

- Talk with the doctor about the likely outcome for the patient. Will it extend life significantly? Will it lead to improvement in the patient's functioning?
- Ask about side effects, pain, or discomfort in providing or not providing food and fluids. For example, in some cases artificial nutrition and hydration can build up fluid in the lungs and other areas. Dehydration does not necessarily cause pain or a

feeling of thirst in a dying patient. Its most frequent symptom, dry mouth, may be treated by ice chips or moistened swabs to the mouth.

- Discuss a possible time period for various treatment options.
- Check the patient's advance directive or try to figure out what the patient would want.
- Whether or not the patient has artificial nutrition and hydration, make sure the medical staff provides comfort care.

Saying no to CPR or artificial nutrition and hydration does not mean no to comfort care.

8. WHAT ABOUT MEDICAL RESEARCH?

Patients who cannot make their own decisions sometimes are eligible to become subjects in a research study. As a proxy, you might be asked to give your permission for the patient to participate in research. The person asking you might or might not be the patient's doctor.

Before deciding, make sure you understand:

- What the research is trying to find out.
- What the patient will have to do as part of the research.
- How being in the research differs from ordinary medical care.
- What the risks are.
- What the possible benefits to the patient are, if any.

Remember, nobody is ever required to participate in research. You might want to give permission if being in the research stands a good chance of benefiting the patient—or even if there is no likely personal benefit, but very little risk. But if being in this research means that the patient might be worse off, without any real chance of direct benefit, just say no.

* The questions on pain were taken from "Pain: Questions to Ask Your Doctor," by the Midwest Bioethics Center, Community-State Partnerships, adapted from the "Rhode Island Consumer Guide to Pain," Joan M. Teno, M.D., Associate Professor of Community Health and Medicine, Brown University Center for Gerontology and Health Care Research, and the "Pain Action Guide," American Pain Foundation, Baltimore, MD.

APPENDIX

The Proxy Quiz: A Tool for Better Understanding

Instructions: As health care proxy, answer these questions in the way you think the patient would answer them. Then ask the patient to answer them and compare your answers. Where the answers differ, discuss why that is.

1. Circle how much you fear the following near the end of life:

	Very Little	Some	Very Much
a. Being in pain	1	2	3
b. Losing the ability to think	1	2	3
c. Being a financial burden on loved ones	1	2	3
d. Losing control over my medical care	1	2	3
e. Losing ability to practice my faith	1	2	3

2. Is it *more important* for you to:

- a. Have your wishes followed at the end of life, even if family members or friends disagree, or
- b. Have family and friends all agree on decisions, even if different from how you would decide, or
- c. I am uncertain.

3. Here are things about end-of-life care that some people believe. Do you agree?

If a dying person can't get enough nutrition by mouth, a feeding tube should always be used if it will keep the person alive.

- a. Yes, I agree
- b. No, I don't agree
- c. I don't know

Once a treatment is started to keep someone alive, it's sometimes okay to decide to stop and withdraw it when the person's quality of life is very low.

- a. Yes, I agree
- b. No, I don't agree
- c. I don't know

It's usually better for a dying person to be given good comfort care at home than to be admitted to a hospital for intensive care.

- a. Yes, I agree
- b. No, I don't agree
- c. I don't know

4. You are very sick, and the doctors cannot stop the disease. With all possible treatments, you might live for another few weeks. During that time, you would be on a breathing machine. You would drift in and out of consciousness. Without these treatments, you would die in a few days. Would you want the breathing machine and other treatments?

- a. Yes, I think so
- b. No, probably not
- c. I don't know

5. You have severe Alzheimer's disease. You can't get out of bed, and you can't recognize or talk with your loved ones, but you are not in pain. You could live like this for many months. However, you get recurring infections which are treated with antibiotics. You get another infection, this time pneumonia. If the doctors give you an antibiotic, you will almost certainly recover from the infection. Without the antibiotic, you will die in a few days.

Do you want the antibiotic if you can otherwise be kept comfortable?

- a. Yes, I think so b. No, probably not c. I don't know

6. You have poor circulation, which resulted in one leg being amputated. Now, your other leg develops gangrene and doctors recommend amputation because it could be fatal. You also have moderate dementia causing mental confusion.

Would you want the operation?

- a. Yes b. No c. I am uncertain

7. You are in a permanent coma and have a tube inserted in your stomach for food and fluids.

Would it be important to you that decisions about your treatment are guided by particular religious beliefs or spiritual values that you hold?

- a. Yes b. No c. I am uncertain

8. You were terminally ill, but a course of treatment might extend your life by six additional months.

Would you want the treatment even though it has severe side effects—pain, nausea, vomiting, and weakness?

- a. Yes b. No c. I am uncertain

IMPORTANT:

THIS IS NOT AN ADVANCE DIRECTIVE. THE QUESTIONS ARE FOR DISCUSSION ONLY

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