

Making Medical Decisions For Someone Else

A New Hampshire Handbook



Are you, or will you be, responsible for managing the health care of someone else? This handbook can guide you through the decisions you may have to make and provide resources for more information.

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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 health care professional, such as a Medical Doctor or Advanced Registered Nurse Practitioner (ARNP), might ask you “What should we do?” When this happens, you are acting as a **health care proxy**—which is the general term for anyone who can make health care decisions for someone else. There are two kinds of proxies recognized under New Hampshire law:

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*.) Often, more than one person will be nominated to act as agent. In that case, the order in which the names are listed is important since it is usually the first person named who will have the authority to make the decisions. In New Hampshire, the decision maker named in this kind of document is called a **health care agent**. The health care agent's authority begins when the person's health care professional certifies in writing that the person no longer has the capacity to make medical decisions. The health care agent's authority ends when the person regains capacity or dies.
2. **A guardian.** A court may appoint you as a **guardian over the person** to make health care decisions for someone else. A guardian is directly answerable to the court. A guardian's authority begins when the judge signs the guardianship order and ends when the judge terminates the guardianship or the person dies.

There are two kinds of health care proxies:

Agent and Guardian.

But in all cases a proxy is a person who can make health care decisions for someone else.

In addition, even when nobody has named you as a health care agent or guardian, you may still be consulted regarding medical decisions for someone else if you are a family member or a close friend.

The authority of an agent or guardian can vary depending on a number of factors. You can learn more about health care agents and guardians by visiting a number of different websites listed at the end of this handbook.

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 agent or guardian, you can make decisions and take actions that a patient would make or do, if able. You may be limited by the terms of the document creating your authority. Some of the decisions you may be able to make include:

- ❖ **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. Further be prepared to provide the document that confers legal authority as it evidences your authority to act.
- ❖ **Talking with the medical team** about treatment choices. Asking questions and getting 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 to be 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 health care professionals, the medical words they use, and the busy hospital. It is a tough job. But there are many places to go for help, so you are not alone. See Section VI for more information on getting help.

- **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.
- **It's not about your money.** Your own money is not at risk in your role as proxy. Being a proxy does not make you owe or pay money to anyone or risk being sued. It is only the patient's money and insurance that is involved. You **cannot** be required to sign personally as the guarantor or responsible party.
- **Inaction has consequences, too.** If you are a proxy, you will be expected to make decisions. The health care professional is relying on you for guidance, so consult with the medical professionals involved and try to sort out the choices.
- **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?



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 New Hampshire law 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.

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.

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

- ❖ Another way you can get the conversation going is by using the **Proxy Quiz** in Appendix 1 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.

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, as a proxy you can use basic steps to help you make decisions on the patient's behalf.

- 1. Find out the medical facts.** This requires talking to the health care professionals 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?

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.

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

- How will this option make the patient improve or feel better?
- Can this procedure be done on a trial basis first? What is a reasonable amount of time for a trial? Is the health care professional 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 health care professional recommend, and why?

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

- In most cases, if you know what the patient would want, New Hampshire law says 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. Review the plan for treatment or care often. As a proxy, you are entitled to read the medical record.
- ❖ **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 health care professional'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.

- Be Visible
- Be Informed
- Be Involved
- Be Heard

- ❖ **Ask for a second opinion, if necessary.** If you disagree with the health care professional or if you are just not sure what to do, get an opinion from another health care professional. If need be, you have the right to transfer the patient to another health care professional 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 whether 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 HEALTH CARE PROFESSIONALS

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

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

Prepare well
for the time
you have
with the
health care
professional.

- ❖ **Present your points or key questions right away.** Ask the health care professional how much time he or she has, and begin with the most important problem first. If you know that 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 health care professionals 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 health care professional 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 health care professional told you in your own words, to be sure there are no misunderstandings.
- ❖ **Take notes** to help you remember what the health care professional says.
- ❖ **Consider bringing a friend or relative** of the patient's with you, at least to the waiting room, to help you remember what to ask and what the health care professional says—and for moral support!

3. Understanding the Patient's Overall Care Plan

Each hospitalized patient and every nursing home resident should have an individualized care plan that describes the individual's treatment goals and how those goals will be achieved. Sometimes this care plan is recorded in a special form.

Remember that as health care agent or guardian, you are a proxy. As the proxy for the individual, you should be familiar with the overall care plan and make sure the plan reflects the patient's values, if known, or otherwise that you think it is in the patient's best interests.

Care Plan Key Components

1. The main goals of care;
2. Whether the patient has an advance directive and contact information for the proxy;
3. How the health care professionals should respond if the patient's heart or breathing stops (e.g. Do Not Resuscitate (DNR));
4. Whether there are other life-sustaining treatment issues that might be particularly important for the patient;
5. Whether medically administered fluids and nutrition should be used if the patient cannot take in enough orally, or whether these should be used for a limited time;
6. Whether a breathing machine should be used if the patient has difficulty breathing, or whether it should be used for a limited time;
7. Whether the patient should be transferred to another health facility.;
8. If the patient develops significant symptoms, whether tests should be done to diagnose the problem, given that many tests cause discomfort or burdens; and
9. Whether antibiotics should be used in case of infection.

As the proxy, you will be included in the development of the care plan. If you have questions about the care plan or if you do not agree with parts of the plan, you should discuss your concerns with the health care professional or ask for a formal care plan meeting. A care plan meeting includes all of the health care team and provides the proxy with an effective way to ask questions, resolve problems and ensure that the care plan best meets the individual needs of the patient or nursing home resident. Bear in mind that your authority to make specific decisions may be limited, particularly with respect to decisions regarding life-sustaining treatment.

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 health care professional advises.

1. WHAT TO DO IF THERE IS A DISAGREEMENT

- **Understand your legal authority.** The proxy has the right to make health care decisions within any limits imposed by the guardianship order, the terms of the advance directive or other court order.
- **Keep the family informed, if appropriate.** You may have the legal authority to make medical decisions but 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. Also refer to Section V of this guide for ideas for a care plan meeting.
- **If conflict persists, ask for an ethics committee meeting if necessary.** Sometimes, these can also be referred to as a hospital or nursing home patient care advisory committee. These committees often are called ethics committees because they 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.
- **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 who visit residents in a nursing home or assisted living facility. 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, call the New Hampshire Long Term Care Ombudsman at (603) 271-4375 or toll free from within New Hampshire at 1-800-442-5640.
- **Probate Court.** As a last resort, seek redress from the Probate Court.

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.
- **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.

- **Palliative Care.** Ask for a palliative care consultation. Many hospitals now have special palliative care teams that focus on a patient's comfort and quality of life and support for his or her family. These teams can often help patients, families and agents through the process of clarifying treatment choices in complex situations.
- **Long-term care resident and family councils.** Residents and family members may organize advisory councils in nursing homes, and sometimes these councils exist in assisted living facilities, 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.
- **Institutional ethics committee or ethics consultant.** These valuable resources were described earlier.

3. GETTING MORE INFORMATION

As a proxy, you may have more questions. Information about the New Hampshire law on advance directives, deciding for others and related issues is available through a number of resources that are listed at the end of this handbook.

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

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, and most private insurance plans and managed care plans. Families and health care professionals 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 Help Line 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

If the patient is in a hospice program, you probably will get special instructions. Hospice can be reached 24 hours a day. You can always **call 911** if there is an emergency

If you call 911, speak clearly and briefly describe the problem. Stay on the line until the dispatcher says you can hang up.

* 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. March 2006

Have **key documents** in a place where you can grab them right away. This includes any of the patient's medical records that are available and any advance directive. Refer to Appendix 2 for a useful checklist to complete. If the patient has a Portable Do Not Resuscitate Order from the doctor or ARNP (see next section), have it ready for the ambulance crew.

5. What About Do Not Attempt Resuscitation (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 lives and this is usually what people want in an emergency. Yet when a patient is seriously or chronically ill and/or death is expected, it may not do much good and can leave the patient worse than before the CPR.

Some people with chronic or serious illness 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 or Advanced Registered Nurse Practitioner (ARNP) must write an in-patient order called a **DNR Order**. A person may also not want CPR outside a health facility. A Portable DNR Order (bright pink form) must be obtained and signed by the proxy, if the patient has not already completed one.

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

- 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.
- Talk with the health care professional 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.

Make sure that the medical staff does not interpret the DNR order to mean no treatment at all. You still want the patient to have **comfort care** and you may want to have treatment for other conditions.

6. What about Surgery?

Sometimes a proxy is asked to consent to surgery that a health care professional 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 about the experience of the surgeon and facility for this particular surgery.
- 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.
- Consider getting a second opinion.

7. What About Medically Administered 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.

Your ability to authorize the withholding or withdrawal of medically administered nutrition and hydration must be stated in the advance directive or appropriate court order.

Feeding tubes help many patients to get the fluids and nutrition they need. They can be lifesavers. 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. Others say that medically administered nutrition and hydration for a seriously ill person sometimes can cause serious complications.

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

- Talk with the health care professional 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 medically administered nutrition and hydration. For example, in some cases medically administered 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. The 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.

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

- Check the patient's advance directive or try to figure out what the patient would want.
- Whether or not the patient has medically administered nutrition and hydration, make sure the medical staff provides comfort care.

8. What About Medical Research or Organ/Tissue Donation?

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. Guardians must petition the Probate Court for permission to consent to experimental research. Health care agents must follow the terms of the advance directive.

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 or experimental treatment.

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.

Organ and Tissue Donation* involves the donation of organs such as a heart, pancreas, kidneys, liver, lungs and intestines and tissue such as bone, tendons, ligaments, corneas, and skin. There is no cost to the donor's family or estate for these donations. In the United States, it is illegal to buy or sell organs and tissue for transplant. The donation process should **not** interfere with the person's medical care. Donation only becomes an option after all life-saving efforts have been made and death declared. Once consent for donation is confirmed, family is asked to participate in the process by providing the patient's medical history. Surgical procedures are used to recover the donated organs and/or tissue. The body is always treated with great care and respect. Donation should not delay or change funeral arrangements. An open casket service is possible.

* Information on organ and tissue donation excerpted from the brochure "You Have the Power to Donate Life" created and disseminated by the New England Organ Bank, A Donate Life Organization.

Appendix 1 - 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, if possible, ask the patient to answer the questions 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 health care professionals 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 health care professionals 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 health care professionals 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. What would you want?

- a. Remove Tube b. Keep Tube c. I am uncertain

8. Describe what other treatment you would want. (Check all that apply and/or list any treatment that you do not see listed.)

- a. Antibiotics b. Artificial Respiration c. CPR d. Other (describe)

9. 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

10. 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

11. Do you wish to donate any organs and/or tissues for transplant or research?

- a. Research b. Transplant c. Both d. Neither

12. If you chose either answer "a," "b" or "c" in question 11, please list the organ(s) and/or tissue(s) that you wish to donate below.

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

Appendix 2 – Emergency Medical Information Checklist

If possible, the following information should be obtained in your initial discussions with the person who has named you as their agent or with the person for whom you have been appointed guardian. If this information is kept current and available it will provide emergency medical professionals with the information they require for a prompt response to the medical emergency. A form has been provided on the next page.

1. Name
2. Date of Birth
3. Address
4. Phone Number
5. Language
6. Cultural or Religious Considerations
7. Physician
8. Diagnosis (all)
9. Allergies
10. Immunization Dates: Tetanus, Pneumonia, Influenza, Other
11. Impaired Vision: Glasses or Contact Lenses
12. Impaired Hearing/Hearing Aid
13. Dentures
14. Swallowing Problem
15. Speech Problem
16. Problem walking: Wheelchair, Walker
17. Metal Implants
18. Pacemaker
19. Prescription Medication
20. Non-Prescription Medication
21. Guardianship Order or Advance Directive
22. Do Not Resuscitate Order
23. Organ/Tissue Donation Authorization

Emergency Medical Information Checklist Form

Name: _____

Date of Birth: _____ Phone Number: _____

Address: _____

Language: _____

Cultural or Religious Considerations: _____

Physician: _____

Diagnosis (all): _____

Allergies: _____

Immunization Dates:

Tetanus: _____ Pneumonia: _____ Influenza: _____

Other: _____

☐ Impaired Vision ☐ Glasses ☐ Contact Lenses

☐ Impaired Hearing ☐ Hearing Aid

☐ Dentures

☐ Swallowing Problem: _____

☐ Speech Problem: _____

☐ Problem walking: ☐ Wheelchair ☐ Walker

☐ Metal Implants _____

☐ Pacemaker

Prescription Medication:

Non-Prescription Medication:

☐ Guardianship Order ☐ Advance Directive

☐ Do Not Resuscitate Order (DNR) ☐ Organ/Tissue Donation Authorization

NEW HAMPSHIRE RESOURCES

Foundation for Healthy Communities www.healthynh.com

Includes Advance Care Planning Guide

New England Organ Bank www.neob.org

Includes information about organ and tissue donation.

New Hampshire Bar Association www.nhbar.org (603) 224-6942

Includes information specific to NH law on estate planning and advance directives, as well as finding a lawyer and other legal services.

New Hampshire Legal Assistance www.nhla.org *toll free* at 1-888-353-9944 or (603) 624-6000

Information on Senior Citizens Law Project, providing legal service to elders.

New Hampshire Probate Court www.courts.state.nh.us/courts/probate

Contains probate court forms and instructions for completing those forms. Also includes information relative to guardianships, estates and other case types.

New Hampshire Quality Care www.nhqualitycare.org

Includes information on New Hampshire hospitals such as ratings on procedures performed at those hospitals.

Service Link Resource Centers www.servicelink.org *toll free* at 1-866-634-9412

Includes information to help individuals make informed decisions in care options for their loved ones. With locations throughout New Hampshire.

ADDITIONAL RESOURCES

American Bar Association Commission on Law and Aging <http://www.abanet.org/aging/>

Medicare <http://www.medicare.gov/>

Includes ratings on Medicare certified providers.

National Academy of Elder Law Attorneys <http://www.naela.org/>

Provides information in the Public section on how to find an elder law attorney, and types of matters where one can assist you.

National Guardianship Association www.guardianship.org

Includes many standards of ethics and practice, including standards for informed consent (standard # 67), decision-making (standard # 7) and decision-making about medical treatment (standard # 14).

National Hospice and Palliative Care Organization <http://www.nhpco.org/>

Making Medical Decisions For Someone Else
