



Sharing Your Wishes™

Give Them Peace of Mind, Not Tough Choices.

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Information Booklet

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Plan ahead for your health care

Why is it important to plan ahead for the last years of your life? Many people would rather not think about it and just deal with whatever happens. But this may mean that you do not receive the kind of care that you want. If you take the time to think about what is important to you, you are more likely to receive health care that fits your beliefs and goals. After you think about what is important to you, share your thoughts and wishes with those who care about you. If you do not plan ahead, family members or other people close to you may not be allowed to make decisions for you, and your wishes can't be followed because no one will know what they are.

If you are like most older adults, you worry about how you will live as you become older and are less able to manage all aspects of your life on your own. Your family, and those who love you, also worry because they know that they might have to step in to help you manage your health care decisions, and they don't know how you want them to handle this responsibility.

It is especially stressful to make difficult decisions at a time of crisis. Planning ahead and having a conversation about your wishes before there is a crisis helps everyone. You don't have to worry and your loved ones don't have to guess. And, if your views differ from those of your family or loved ones, planning ahead gives you the opportunity to share what is important to you to avoid conflict later if you can't make decisions for yourself.

The time to talk is now. Share what is important to you. This will greatly reduce the uncertainty and anxiety for those who care about you; instead you provide them with direction and peace of mind.



Do you have an advance directive?

Every time you go to a medical facility someone will ask you if you have an advance directive. The term advance directive refers to several different types of documents: Health Care Proxy, Living Will, and Do Not Resuscitate Order. Any of these documents gives instructions for future health care in the event you are not able to make decisions for yourself.

Health Care Proxy

The best way to protect your treatment wishes and concerns is to appoint someone you trust to make decisions for you. New York State Proxy Law allows you to pick a person as your health care agent to speak for you if you are no longer able to speak for yourself (if you are eighteen or older). Your health care agent will be allowed to make all of your health care decisions including decisions to use or remove treatments that may extend your life, and whether you will have any medical tests, treatments, or surgeries. Your agent needs to know your wishes about artificial nutrition and hydration (food and water provided by a feeding tube), or he or she will not be allowed to refuse or agree to these measures for you.

Your agent will start making decisions for you when doctors decide that you are not able to make health care decisions for yourself. The Sharing Your Wishes Planning Guide will help you complete a New York State Health Care Proxy form.

It is difficult to know what health care decisions will need to be made in the future, so the best way to plan is to choose an agent now to make decisions for you if you are unable to make them yourself. Your health care agent can talk to your doctor and review your medical record to make decisions that he or she believes you would have wanted. In New York State, if you do not select a health care agent and complete a Health Care Proxy form, your family will not be able to make health care decisions for you if you lose capacity.

Living Will

A living will allows you to make decisions in advance and prepare written instructions about your health care if you become either terminally ill or have an irreversible condition and you are no longer able to speak for yourself. For example, you might use a living will to state specific treatments that you would want, and not want, if you are in a coma and there is no hope of your recovery. A living will is not a legally recognized document in New York

Bob is 79 years old and recently had a stroke. He has some problems speaking clearly but can understand others.

With a little help he can dress and care for himself, and with a walker he can get around pretty well. Before his stroke he was scheduled to have a total hip replacement.

Now that some time has passed since the stroke and he is doing better, his doctor asks if he wants to re-schedule the surgery for the hip replacement.

After the surgery he will have about six months of therapy and exercise but then he will have much less pain in his hip. His doctor thinks he is medically stable enough for the surgery.

If this were you, would you want the surgery?

(Living Will Continued)

State, but it can be help your agent and caring professionals understand your wishes by providing clear and convincing evidence of the care you want, and don't want. A living will cannot be used to name someone to make decisions for you.

You should understand that general instructions about refusing treatment, even if written down, may not be effective. Your instructions must be clear and understandable. For example, if you just write down that you do not want "heroic measures," this instruction may not be specific enough. Your instructions should be specific for medical conditions where recovery is not expected including coma, severe brain damage or terminal illness. The living will should say the kind of life-sustaining treatment that you want, or do not want, such as a respirator or chemotherapy, for each condition. Putting things in writing is safer than simply speaking to people. But, the best plan is to appoint a health care agent to decide for you if you are not able to make decisions yourself.

Do Not Resuscitate Order

You may decide, after talking with your doctor, that you do not want emergency treatment to restart your heart and lungs if your heartbeat or your breathing stops. You have the right to decide about cardiopulmonary resuscitation (CPR).

A Do Not Resuscitate Order lets you express your wish to avoid emergency treatment to restart your heart and lungs. A Do Not Resuscitate Order form requires your doctor's signature and periodic review. If you do not have this form, emergency medical personnel (including doctors, nurses and ambulance paramedics) are required to attempt to restart your heart.

If you are in a hospital or nursing home, a hospital DNR form is used. If you are at home or in a hospice or medical clinic, you will need a Non-Hospital DNR Order. If your physical or mental condition prevents you from deciding about CPR, someone you appoint—your family members or others close to you—can decide for you. This decision does not require a health care agent.

Medical Orders for Life-Sustaining Treatment (MOLST)

The MOLST Program is designed to improve the quality of care people receive at the end of life. It is based on effective communication of patient wishes, documentation of medical orders on a brightly colored pink form and a promise by health care professionals to honor these wishes.

The MOLST form is a bright pink medical order form signed by a New York State licensed physician that communicates patient wishes regarding life-sustaining treatment to health care providers. These valid medical orders must be followed by all health care professionals in all sites of care, including the community.

The form includes medical orders and patient preferences regarding CPR (cardiopulmonary resuscitation), intubation and mechanical ventilation, artificial hydration and nutrition, antibiotics, and future hospitalization and transfer.

For further information, view www.CompassionandSupport.org.

Four easy steps to plan ahead for your health care decisions

1. Think about what is important to you and how you want to receive your care.

The questions in the section **Think about Your Health Care Wishes** and in the **Sharing Your Wishes Planning Guide** will help you think about the things that are important to you. The short stories in this booklet can also help you think about the possible health decisions that may lie ahead.

2. Select a person to speak for you if you are unable to speak for yourself.

Who would you trust to make decisions for you if you are unable to make them for yourself? Is there anyone else that you want your agent to talk with before making decisions about your care? Is there someone else (an alternate) who could make these decisions if your health care agent is not able to act for you?

When you decide on a person to be your health care agent, it is important that you discuss the responsibilities of a health care agent and know that the person you select accepts this responsibility.

3. Talk about your health care wishes.

Once you have selected a person to be your health care agent, the next step is to talk with him or her about your health care wishes. The more your agent understands about your wishes, beliefs and goals, the easier it will be if he or she needs to step in to make health care decisions for you.

4. Put your choices in writing.

Sharing your wishes is important, but you must also prepare a New York State Health Care Proxy Form to give your agent the right to make health care decisions for you if your doctor decides you are not able to make them yourself.

Edna has dementia and is often confused, especially by changes in her routine.

She lives with her daughter and family and enjoys spending time with her grandchildren and working in the garden.

She is in generally good health except that she is having trouble seeing clearly.

Her doctor has suggested that she have cataract surgery.

If this were you, would you want the surgery?

The Sharing Your Wishes Planning Guide is a helpful tool for completing a New York State Health Care Proxy Form and beginning a conversation with your health care agent. Ask for a copy from the Coalition nearest you. You can ask for information about living will, MOLST, or DNR forms from the Coalition, or your doctor.

Share your wishes

Your advance directive forms should be available for your health care agent, family, loved ones, doctors, and spiritual advisors to reference if they are faced with difficult decisions and you are not able to state your opinions. Don't put your advance directive documents away in a "safe place" that nobody knows but you. Make copies of your completed forms so that your health care agent, and others who may be involved in your care, have copies or know where to find them if they are needed. Give a copy to your personal physician.

If your county's coalition is participating in free on-line storage of advance directives, send in your forms so health care providers will have access to them from anywhere you need care.

Remember advance care planning is not something that you should do just once in your life. Changes in your health, or living status, may change what is important to you and how you wish to live now and in the future.



Think about your health care wishes

There are many things to think about when you consider your health wishes. This is especially important before you become seriously ill, or have a terminal or irreversible medical condition. The following questions will help you think about your health care wishes.

1. What medical care options are available for you and what are the chances they will improve your condition or prolong your life? What are the possible side effects or complications? What kinds of treatments do you want? What don't you want?
(Talk with your doctor if you have questions)
2. What are your goals for your care? How important is it that you are free of pain? How important is it to you to be completely alert even if this means you have more pain? Do you want life saving procedures performed like starting your heart again? Are there situations where you are so seriously ill that you would want to refuse treatment that might prolong your life? Do you want only those treatments that are necessary to make you feel better? Is it more important that you are comfortable or that you live longer? Would your treatment decisions be different if continued treatment or additional treatments will not improve your life and may only prolong or even cause more discomfort and suffering?
3. Would you want treatments that might prolong your life if you are
 - a. No longer able to think for yourself?
 - b. No longer able to communicate?
 - c. No longer able to recognize those you love?
 - d. Terminally ill or near death?
 - e. Unconscious and unlikely to regain consciousness?
4. What is important in your life? What do you like to do and what do you want to be able to continue doing? Perhaps what is important is the ability to spend time with loved ones, spiritual advisors, or a beloved pet. Perhaps you enjoy music or a special view. Be sure to share those things that are important to you so that your loved ones can support your wishes later. How do your cultural and religious values influence your decisions?
5. Who do you want to take care of you? Where do you want to be living at the end of your life?

Remember you don't have to make these difficult decisions alone. You can discuss your wishes and thoughts with the important people in your life: your family, a close friend, your doctor, and your spiritual advisor. You can also talk with nurses, social workers or others providing your care. There also may be a support group available to help you.

Cora has chronic lung disease and has been hospitalized four times in the last year. Twice she has been put on a breathing machine for a short period of time.

She is on oxygen all the time. She frequently becomes short of breath. In fact, she finds it difficult to even manage her daily routines. It takes her a very long time just to get dressed in the morning.

She develops a fever and other symptoms that cause her home health nurse to think that she might have pneumonia.

The nurse suggests that she should go to the hospital for IV antibiotics.

If this were you, would you want to go to the hospital for antibiotic treatment, or would you prefer to be kept comfortable at home and let nature take its course?

Understand health care choices

When a health care decision needs to be made, it is important to gather information to make an informed decision. Many treatments will have both positive and negative sides to consider. They may cause pain, or require rehabilitation, or require hospitalization.

When making a health care decision, it is important to consider the benefits and burdens of the treatment options by talking with your doctor about the following:

- Will the treatment make a difference?
- Will I be cured, or recover abilities, or be relieved of pain or other symptoms?
- How will I be after the treatment? How will it affect my life?
- Is the treatment difficult to handle?
- How long is the recovery period and what will I need to do?

It is important to learn enough about the treatments to decide if the benefit is worth the burden. Sometimes a treatment will eliminate a problem, such as antibiotics to get rid of an infection. Sometimes a treatment is used to relieve pain and suffering, or to improve function. Some treatments will prolong life and other treatments prolong the dying process.

It is difficult to predict medical situations to make health care decisions in advance. Also, advances in treatment are developing all the time and new choices may be available in the future. So, the most important thing is to talk about your personal beliefs and values, related to what you know about your medical conditions, to help your health care agent know what is important to you.

For some treatments, when the outcome is unpredictable, you can agree to a short-term trial. For example, short-term use of a ventilator may help with breathing to allow the body to heal and stabilize. A trial period can be discussed with your doctor. At the end of the trial period, you can choose to continue or stop the treatment.

You may want to give your health care agent special instructions on some possible medical treatments about which you have strong opinions. Some examples of these treatments are provided for your consideration.

Antibiotic therapy

Antibiotic therapy uses pills, injections or intravenous methods to provide drugs to combat infections. Many infections like pneumonia and urinary tract infections can be cured with antibiotics. At the last phase of life, some people will choose not to use antibiotics for such things as pneumonia to allow a peaceful death from the disease.

Artificial hydration and nutrition (food and water provided by feeding tube)

Artificial hydration and nutrition uses tubes to provide nutrition (food) and hydration (fluid) to replace or add to ordinary eating and drinking. The tube is placed in the nose to go down your throat to your stomach, or inserted by needle into a vein, or by surgery into the stomach or upper intestine.

Artificial hydration and nutrition can save lives when used while the body is healing. Long-term use may be important for people with serious intestinal problems that make eating impossible. Artificial hydration and nutrition are also considered when people have irreversible conditions or are near death.

Medical personnel will insert artificial hydration and nutrition tubes unless you or your agent make the decision not to use this treatment. Often, in these cases, the treatment will not reverse the course of the disease or improve the quality of life. In fact, the treatment sometimes prolongs the dying process. When a person is dying, the body naturally adjusts to the absence of food and fluid and the person does not starve to death.

Artificial respiration or mechanical ventilator

A mechanical ventilator is used to support or replace the function of the lungs in breathing. A machine is attached to a tube that is inserted through the nose or mouth into the windpipe. This machine forces air into the lungs. Ventilators are used both for short-term treatment to help a person recover from illness, and long-term for people with irreversible breathing problems.

For a person who is dying, use of a ventilator often prolongs the dying process, keeping the person alive until another body system fails. Ventilation provides oxygen but it does not improve the cause of the breathing problem.

Cardiopulmonary resuscitation (CPR)

Cardiopulmonary resuscitation means the use of treatments to restart the heart and lungs. This may include pressing hard on your chest to keep your blood pumping, mouth to mouth breathing, electrical shocks to jump start your heart, and/or drugs injected into your veins to stimulate the heart.

When used quickly, after a heart attack or drowning, CPR can save lives. However, for older adults with chronic health problems, very few will recover after CPR. Other complications can also occur for older adults who do survive: ribs may be broken, internal organs may be damaged, and if the process took too long, brain damage may result. Medical personnel will attempt CPR unless you have a Do Not Resuscitate Order.

to be continued on the next page

Comfort Care

Sometimes in the last phase of life, the goal for treatment changes from cure to comfort care. This means that treatment will focus on compassionate care and the management of symptoms. Comfort care does not mean “no care.” Comfort care includes such things as pain management, nursing care to maintain cleanliness and prevent skin breakdown, and oxygen to support breathing but not a mechanical ventilator. Comfort care also includes emotional and spiritual support for the person and those close to them.

Elective Procedures

Many surgeries and other treatments are considered elective. This means that they are not necessary to sustain your life but may add comfort, improve your function, or prevent a possible problem in the future. Elective procedures include such things as colonoscopy, joint replacements of hips or knees, dental procedures, and some skin cancer removals.

Dialysis

The body’s kidneys may fail slowly from a long illness, or very quickly from illness, making it impossible for the kidneys to adequately clean the blood. Dialysis is necessary in these cases to remove impurities from the blood because the kidneys can no longer do this. Dialysis may be useful for a short period of time while the body heals, or it may become a necessary treatment for the rest of your life. Most people who are on dialysis for long-term treatment and who choose to stop the dialysis will die naturally and peacefully within about a week.

Pain Management

Pain management has become very effective. Most pain can be controlled. Some of the strongest pain medications can cause drowsiness so some people will decide to live with some pain to be more alert. Pain medications do not shorten a person’s life.

Decisions will include both starting and stopping treatments, as well as short-term treatment trials. All are important decisions and should be made according to your wishes. To help make the best decisions, it is important to discuss your medical condition with your doctor and to ask questions about the choices you or your agent may need to make. It is legally and ethically appropriate to stop a treatment that is no longer effective and is not helping the person. If death is the result, it is the underlying disease, not the withdrawal of treatment that causes the death.



Frequently asked questions

Q: Does a health care proxy give a health care agent authority to only make decisions about life-sustaining treatment?

A: No. An agent can make **all** health care decisions that the patient could make while capable, from routine treatment decisions to decisions about life-sustaining treatments, unless stated otherwise by the person who writes the proxy form.

Q: Why is it important to name someone as your health care agent?

A: If you do not have a health care agent, your doctor may be required to provide you with medical treatment that you would have refused if you were able to do so. This is particularly important for treatments that will keep you alive even if you have no hope of recovery.

Q: Won't my spouse or family be able to make decisions about my health care?

A: At this time in New York, the only way to ensure that someone you trust will be able to make decisions about your health care is to appoint a health care agent. Family members have no legal authority to make decisions for you.

Q: When is it important to name a health care agent and to have a conversation about health decisions and how you want to be cared for in the last phase of your life?

A: Anytime and soon, while you are able to understand your medical condition and able to share your wishes. Because this is a difficult discussion many people put it off until a health crisis forces the conversation. It is much easier to have this conversation before important decisions need to be made.

Q: Who can be a health care agent?

A: Any adult (18 or older) can serve as your health care agent. This person cannot be your doctor or an employee of a health care provider responsible for your care, unless he or she is a family member. If you select a doctor as your agent, he or she will have to choose between acting as your agent or being your doctor.

Q: Is a health care proxy only for people to refuse treatment?

A: No. The proxy is a vehicle to plan for the loss of decision-making capacity. It is just as valuable for people who want to receive every treatment possible. The health care proxy allows you to choose a family member or someone you trust to decide about treatment choices according to your wishes.

Q: When does my health care agent assume responsibility for my care?

A: Your health care agent becomes responsible only when your doctor determines that you are unable to make decisions. Until then, you continue to be in charge of making your own health care decisions. Specifically the New York State Proxy Law states capacity to make health care decisions is defined as “the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of and alternatives to any proposed health care, and to reach an informed decision.”

Before your agent makes a decision to withdraw or withhold any life-sustaining treatment, your doctor must get an opinion from another doctor to confirm that you are unable to make this decision.

If you object to a health care decision made by your agent, your doctor will follow your wishes unless a court has determined you are not competent to make health care decisions.

Q: How long is my health care proxy effective? Can it be changed?

A: Your health care proxy is effective until your death. You should review it periodically because your personal and health situation may change. You can change your choice of health care agent or your living will at any time by creating a new document. Your health care proxy will automatically become invalid if your spouse is your health care agent and you are legally separated or divorced.

Q: When does a living will come into effect?

A: A living will is used as a guide when your health care agent and others must make decisions for you and takes effect when you have an irreversible or terminal illness.

Q: Does writing a living will mean that treatment will be withheld?

A: Preparing a living will does not mean you will receive no treatment. It means that you are more likely to receive the treatment that meets your wishes. Even if you say that you do not want treatments that will prolong your life, you can still receive treatments that will make you comfortable.

Q: Will doctors and health care providers follow advance directives?

A: A health care proxy is a legal document and doctors are required to follow its instructions. It is important to share a copy of your health care proxy form and to discuss your wishes with your doctor in advance to avoid conflict and uncertainty when decisions need to be made.

Q: Do I need a lawyer to complete an advance directive?

A: No, a lawyer is not needed to complete any advance directive document, including a health care proxy or living will. Also, you do not need to notarize your advance directive documents.

Q: How does a health care proxy differ from a power of attorney?

A: A health care proxy is not a power of attorney. A power of attorney gives a person the authority to act for you in business matters for such things as making financial decisions or paying bills. A health care proxy gives a person the authority to make health care decisions for you if you are no longer able to make these decisions. New York State law requires that the health care proxy is a separate document.

Q: Will my advance directive forms be honored in other states if I travel?

A: Each state has its own laws about advance directives. If the New York State forms comply with the laws of that state they must be honored. If you travel to another state you can learn about their laws through that state's Department of Health.

For more information:

Sharing Your Wishes™ is a project of thirteen community coalitions in western and central New York. Contact the Coalition nearest you for more information.

Allegany County:
Community Partnership
on Aging
(585) 593-5223

Cattaraugus County:
Community Coalition for
Advance Care Planning
(716) 373-8032 or
1 (800) 462-2901

Cayuga County:
Office for Aging
(315) 253-1226

Erie County:
Hospice Buffalo
(716) 686-8070

Genesee County:
Long Term Care Task Force
(585) 343-1611

Niagara County:
Council For Older Adults
(716) 285-8224 ext 215

Onondaga County:
Sharing Your Wishes
Community Coalition
(315) 426-0485 ext 390

Orleans County:
Long Term Care Task Force
(585) 589-3102

Steuben County:
Steuben County Office
for the Aging
(607) 664-2298 Bath
(607) 324-4891 Hornell
(607)936-4661 Corning

Schuyler County:
Office for the Aging
(607) 535-7108

Tompkins County:
Health Planning Council of
the Human Services Coalition
(607) 273-8686

Wyoming County:
Long Term Care Council
(585) 786-6114

Louis is 80 years old and his kidneys are failing making him weak and unable to do anything but sit in a chair and watch television all day.

He has been told that he needs to begin kidney dialysis to keep him alive.

He understands this means that he will have some good days and that he will feel able to get out of the house.

But, he will spend hours every few days at the dialysis center receiving the treatment.

**If this were you,
would you want dialysis?**



Supported by a grant from the Health Foundation for Western and Central New York. The Health Foundation for Western and Central New York is an independent private foundation that sparks lasting change in health and health care across western and central New York, with a special focus on young children, vulnerable older adults and the systems serving them.

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American Bar Association's Consumer's Tool Kit for Health Care Advance Planning available at www.abanet.org/aging/toolkit/home.html

Hard Choices booklet available at www.hardchoices.com in English and Spanish.

Caring Connections, for state-specific documents. www.caringinfo.org



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