Deciding About Health Care

A GUIDE FOR PATIENTS AND FAMILIES

New York State Department of Health

Introduction

Who should read this guide?

This guide is for New York State patients and for those who will make health care decisions for patients. It contains information about surrogate decision-making in hospitals and nursing homes. It also covers DNR orders in a health care facility, or in the community. Because this guide is about health care decision-making, the word "patient" is used to refer to anyone receiving medical care. This includes a nursing home resident. This guide does **not** include the special rules for health care decisions made by legal guardians of persons with developmental disabilities.

Can the patient or other decision maker find out about the patient's medical condition and proposed treatment?

Yes. Patients or other decision makers have a right to be fully informed by a doctor about their medical condition and the doctor's proposed treatment. Patients must give informed consent before any non-emergency treatment or procedure. Informed consent means that after information is given about the benefits and risks of treatment (as well as alternatives to the treatment) permission is given to go ahead with the treatment.

Adult Patients Who Have the Ability to Make Informed Decisions

Do adult patients have a right to make their own health care decisions?

Yes. Adult patients have the right to make treatment decisions for themselves as long as they have decision-making capacity.

What is "decision-making capacity"?

"Decision-making capacity" is the ability to understand and appreciate the nature and consequences of proposed health care. This includes the benefits and risks of (and alternatives to) proposed health care. It also includes the ability to reach an informed decision.

What if it's unclear whether or not a patient has decision-making capacity? Who decides whether or not the patient has capacity?

Health care workers will assume patients have decision-making capacity, unless a court has appointed a legal guardian to decide about health care. A doctor will examine the patient if there is good reason to believe the patient lacks capacity. A doctor must make the determination that a patient lacks the ability to make health care decisions. Another person will make health care decisions for the patient only after the patient's doctor makes this determination.

Do family members always make health care decisions whenever patients lack decision-making capacity?

No. Sometimes patients have already made a decision about a procedure or treatment before they lose the ability to decide. For example, a patient can consent to surgery that involves general anesthesia before receiving anesthesia, which would cause them to lose the ability to decide. Other times, a healthy person may suddenly lose capacity. In this case, health care may need to be given right away without consent. For example, a person may be knocked unconscious during an accident. Health care providers will provide emergency treatment without consent unless they know that a decision has already been made to refuse emergency treatment.

Advance Directives/ Health Care Proxies

What is an advance directive?

Advance directives are written instructions about health care treatment made by adult patients before they lose decision-making capacity. In New York State, the best way to protect your treatment wishes and concerns is to appoint someone you trust to decide about treatment if you become unable to decide for yourself. By filling out a form called a health care proxy, this person becomes your "health care agent."

Before appointing a health care agent, make sure the person is willing to act as your agent.

Discuss with your agent what types of treatments you would or would not want if you were in the hospital and had a life-threatening illness or injury. Make sure your health care agent knows your wishes about artificial nutrition and hydration (being fed through a feeding tube or IV line). You can get more information about health care proxies at: **https://www.health.ny.gov/professionals/patients/health_care_proxy/**

Some patients also express specific instructions and choices about medical treatments in writing. A written statement can be included in a health care proxy, or it can be in a separate document. Some people refer to this type of advance directive as a "living will."

How do health care agents make decisions under a health care proxy?

Health care agents make decisions just as if the health care agent were the patient. The health care agent makes health care decisions according to the patient's wishes, including decisions to withhold or withdraw life-sustaining treatment. If the patient's wishes are not reasonably known, health care agents make health care decisions in accordance with the patient's best interests.

Can a health care agent decide to withhold or withdraw artificial nutrition or hydration (through a feeding tube or an IV line)?

Health care agents can only make decisions to withhold or withdraw artificial nutrition and hydration under the health care proxy if they know the patient's wishes about the treatment. But, the health care agent may also be able to make this type of decision in a hospital or nursing home as a surrogate from the surrogate list set forth in law.

Health Care Decision-Making in Hospitals and Nursing Homes

How do adult patients with decision-making capacity make decisions in hospitals and nursing homes?

Patients may express decisions verbally or in writing. A hospital patient or nursing home resident may not verbally make a decision to withhold or withdraw life-sustaining treatment unless two adults witness the decision. One of the adults must be a health care practitioner at the facility. If a patient does not now have capacity to make a decision (but made a decision in the past about the proposed health care), the hospital or nursing home will act based on the patient's previously made decision. This is true unless something occurs that the patient did not expect and the decision no longer makes sense.

How are health care decisions made for a hospital patient or nursing home resident who does not have capacity?

If the patient has a health care proxy, the health care agent named in the proxy makes decisions. If a patient does not have a health care proxy, a legal guardian (or the person highest in priority from the surrogate list, known as "the surrogate") makes decisions.

What is the surrogate list?

Below is the surrogate list. The person who is highest in priority is listed at the top. The person with the lowest priority is at the bottom.

- The spouse, if not legally separated from the patient, or the domestic partner;
- A son or daughter 18 or older;
- A parent;
- A brother or sister 18 or older; and
- A close friend.

What is a "domestic partner"?

A "domestic partner" is a person who:

- has entered into a formal domestic partnership recognized by a local, state or national government.
  Or, this person has registered as a domestic partner with a registry maintained by the government or an employer; or, this person
- is covered as a domestic partner under the same employment benefits or health insurance; or, this person
- shares a mutual intent to be a domestic partner with the patient, considering all the facts and circumstances, such as:

- They live together.
- They depend on each other for support.
- They share ownership (or a lease) of their home or other property.
- They share income or expenses.
- They are raising children together.
- They plan on getting married or becoming formal domestic partners.
- They have been together for a long time.

Who cannot be a domestic partner?

- A parent, grandparent, child, grandchild, brother, sister, uncle, aunt, nephew or niece of the patient or the patient's spouse.
- A person who is younger than 18.

Who qualifies as a "close friend"?

A "close friend" is any person, 18 or older, who is a friend or relative of the patient. This person must have maintained regular contact with the patient; be familiar with the patient's activities, health, and religious or moral beliefs; and present a signed statement to that effect to the attending doctor.

What if a surrogate highest in priority is not available to make the decision?

If this happens, the next available surrogate who is highest in priority makes the decision.

What if a surrogate highest in priority is unable or unwilling to make the decision?

In this case, another person from the surrogate list will decide. The surrogate highest in priority may designate any other person on the list to be surrogate, as long as no one higher in priority than the designated person objects.

Can patients or other decision makers change their minds after they make a treatment decision?

Yes. Decisions may be revoked after they are made by telling staff at the hospital or nursing home.

Decisions to Withhold or Withdraw Life-Sustaining Treatment in Hospitals and Nursing Homes

What is "life-sustaining treatment"?

"Life-sustaining treatment" means that the attending doctor believes the patient will die within a relatively short time if the patient does not get the medical treatment or procedure. CPR is always considered to be life-sustaining treatment.

What is CPR?

CPR (cardiopulmonary resuscitation) refers to medical procedures that try to restart a patient's heart or breathing when the patient's heart stops and/or the patient stops breathing. CPR may begin with something like mouth-to-mouth resuscitation and forceful pressure on the chest to try to restart the heart. This may not work, so CPR may also involve electric shock (defibrillation); insertion of a tube down the throat into the windpipe (intubation); and placing the patient on a breathing machine (ventilator).

What is a decision to withhold or withdraw life-sustaining treatment?

A decision to withhold life-sustaining treatment is deciding to refuse a treatment before it is provided. A decision to withdraw life-sustaining treatment is deciding to refuse treatment already being provided. Every adult patient has the right to refuse medicine and treatment after being fully informed of (and understanding) the probable consequences of such actions.

How would a hospital or a nursing home carry out a decision to withhold or withdraw life-sustaining treatment?

The doctor might direct staff not to provide, or to stop providing, certain medicines, treatments or procedures. This may result in the patient dying within a relatively short time. For example, the doctor might order that a ventilator, which is enabling a patient to breathe, be turned off.

In order to withhold life-sustaining treatment, the doctor might issue a medical order such as a:

- Do Not Resuscitate (DNR) Order: this means do not attempt CPR when the patient's heart stops and/or the patient stops breathing.
- Do Not Intubate (DNI) Order: this means do not place a tube down the patient's throat or connect the patient to a breathing machine (ventilator).

A decision could also be made to stop (or not to start) artificial nutrition and hydration through a feeding tube or an IV. This means the facility will not give the patient liquid food or fluids through a tube inserted in the stomach – or by a tube called a catheter inserted into the patient's veins. Patients will always be offered food to eat and fluids to drink by mouth if they are able to eat and drink.

Other kinds of decisions to limit medicines, treatments or procedures could also be followed (for example, stopping dialysis).

Will a hospital or a nursing home ever withhold all treatment?

No. Even if a patient has a DNR order or other medical order to withhold life-sustaining treatment, the patient should receive medical care and treatment to relieve pain and other symptoms and to reduce suffering. Comfort care, also known as palliative care, should be available to all patients who need it.

When should a patient get a DNR order?

Any adult with decision-making capacity may request a DNR order. However, patients and families must consult with a doctor about their diagnosis and the likely outcome of CPR.

Only a doctor can sign a DNR order. A DNR order instructs health care professionals not to provide CPR for patients who want to allow natural death to occur if their heart stops and/or if they stop breathing. For example, a patient who is expecting to die from a terminal illness may want a DNR order.

When successful, CPR restores heartbeat and breathing. The success of CPR depends on the patient's overall medical condition. Age alone does not determine whether CPR will be successful. But illnesses and frailties that go along with age often make CPR less effective. When patients are seriously ill, CPR may not work or it may only partially work. This might leave the patient brain-damaged or in a worse medical state than before his or her heart stopped. After CPR (depending on the patient's medical condition), the patient may be able to be kept alive only on a breathing machine.

Does a DNR order affect other treatment?

No. A DNR order is only a decision about CPR – chest compression, intubation and mechanical ventilation – and does not relate to any other treatment. Do not resuscitate does **not** mean do not treat.

What happens if the patient is transferred from the hospital or nursing home to another hospital or nursing home?

Medical orders, including a DNR order, will continue until a health care practitioner examines the patient. If the doctor at the new facility decides to cancel the medical order, the patient or other decision maker will be told and he or she can ask that the order be entered again.

Decision-Making Standards for Legal Guardians and Surrogates in Hospitals and Nursing Homes

How are health care decisions made by surrogate decision makers, including legal guardians?

The surrogate must make health care decisions in accordance with the patient's wishes, including the patient's religious and

moral beliefs. If the patient's wishes are not reasonably known, the surrogate makes decisions according to the patient's "best interests." To figure out what is in the "best interests" of the patient, the surrogate must consider: the dignity and uniqueness of every person; the possibility of preserving the patient's life and preserving or improving the patient's health; relief of the patient's suffering; and any other concerns and values a person in the patient's circumstances would wish to consider. In all cases, what matters is the **patient's** wishes and best interests, not the surrogate's. Health care decisions should be made on an individual basis for each patient. Again, decisions must be consistent with the patient's values, as well as religious and moral beliefs.

Do surrogates always have authority to consent to needed treatments?

Yes.

Do surrogates always have authority to make decisions to withhold or withdraw life-sustaining treatment?

No. A legal guardian or a surrogate in a hospital or nursing home may decide to refuse life-sustaining treatment for a patient only in the following circumstances:

- Treatment would be an extraordinary burden to the patient and:
  - the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or
  - the patient is permanently unconscious;

  or
  - The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances and the patient has an irreversible or incurable condition. In a nursing home, an ethics review committee must also agree to decisions (other than DNR) based on this bullet-point. In a hospital, the attending doctor or the ethics review committee must agree to a decision to withhold or withdraw artificial nutrition and hydration based on this bullet-point.

How are decisions about life-sustaining treatment made for minors in a hospital or nursing home?

The parent or guardian of a patient under 18 makes decisions about life-sustaining treatment in accordance with the minor's best interests. They take into account the minor's wishes as appropriate under the circumstances. For a decision to withhold or withdraw life-sustaining treatment, the minor patient must also consent if he or she has decision-making capacity. It is assumed that an unmarried minor lacks decision-making capacity unless a doctor determines that the patient has the capacity to decide about life-sustaining treatment. Minors who are married make their own decisions, the same as adults.

What if an unmarried minor patient has decision-making capacity and he or she is a parent? What if he or she is 16 or older and living independently from his or her parents or guardian?

Such minors can make decisions to withhold or withdraw life-sustaining treatment on their own if the attending doctor and the ethics review committee agree.

Resolving Disputes in Hospitals and Nursing Homes

What if there are two or more persons highest in priority and they cannot agree? For example, what if the adult children are highest in priority and they disagree with one another?

In this case, the hospital or nursing home staff can try to resolve the dispute by informal means. For example, more doctors, social workers or clergy could discuss the decision. Also, every hospital and nursing home must have an ethics review committee. The case may be referred to the ethics review committee for advice, a recommendation, and assistance in resolving the dispute. The hospital or nursing home must follow the decision of the surrogate that is based on the patient's wishes, if they are known. If the patient's wishes are not reasonably known, the hospital or nursing home must follow the decision that is in the patient's best interests.

What if a person connected with the case does not agree with the surrogate's treatment decision? This could be the patient, a health care worker treating the patient in the hospital or nursing home or someone lower in priority on the surrogate list.

Again, the hospital or nursing home staff can try to resolve the dispute by informal means. If that is not successful, the person who disagrees could request help from the ethics review committee. The person challenging the decision maker can ask that the ethics review committee try to resolve the dispute. This person could present information and opinions to the committee. The ethics review committee can provide advice and make a recommendation, and can provide assistance in resolving the dispute.

Are the recommendations and advice of the ethics review committee binding?

No, the recommendations and advice of the ethics review committee are advisory and non-binding, except for three very specific types of decisions. The ethics review committee must

agree with the decision in the following three situations:

- A surrogate decides to withhold or withdraw life-sustaining treatment (other than CPR) from a patient in a nursing home. The patient is not expected to die within six months and is not permanently unconscious. In this situation, the ethics review committee must agree to the following. The patient has a condition that can't be reversed or cured. Also, the provision of life-sustaining treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances.
- A surrogate decides to withhold or withdraw artificial nutrition and hydration from a patient in a hospital. The attending doctor objects. The patient is not expected to die within six months and is not permanently unconscious. In this situation, the ethics review committee must agree to the following. The patient has a condition that can't be reversed or cured. Also, artificial nutrition and hydration would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances.

- In a hospital or nursing home, an ethics review committee must approve the decision of an unmarried, emancipated minor to withhold or withdraw life-sustaining treatment without the consent of a parent or guardian.
- A physician decides to admit into hospice a patient who lacks capacity and who does not have a health care proxy or surrogate. The committee must also review the hospice plan of care, which can include the withholding or withdrawal of life-sustaining treatment if the standards are met for surrogate decision about such treatment.

In these three situations, life-sustaining treatment will not be withheld or withdrawn unless the ethics review committee approves.

What does it mean when the recommendations and advice of the ethics review committee are advisory and non-binding?

This means that the surrogate highest in priority can make a legal health care decision. He or she can do this even if another person lower in priority on the surrogate list or others continue to disagree with the surrogate decision maker.

What if the hospital or nursing home has a policy based on religious or moral beliefs that prevents the facility from honoring a health care decision?

When possible, the facility must inform patients or family members of this policy before or at admission. When the decision is made, the facility must cooperate in transferring the patient to another facility that is reasonably accessible and willing to honor the decision. Meanwhile, the facility must honor the decision, unless a court rules otherwise. If the decision goes against one health care practitioner's religious or moral beliefs, the patient must be promptly put under the care of another health care practitioner.

DNR Orders Outside the Hospital or Nursing Home

If a patient is not in a hospital or nursing home, how can the patient get a DNR order or DNI order?

The patient's doctor can write a DNR order on a standard form that has been approved by the New York State Department of Health: DOH-3474 (Nonhospital Order Not to Resuscitate). A doctor can also sign a nonhospital DNI order in addition to the nonhospital DNR order using the DOH-5003 form called MOLST (Medical Orders for Life-Sustaining Treatment). EMS, home care agencies and hospices must honor these orders.

If the patient is at home with a nonhospital DNR order, or MOLST orders, what happens if a family member or friend calls an ambulance?

If the patient has a nonhospital DNR order and it is shown to emergency personnel, they will not try to resuscitate the patient or take the patient to a hospital emergency room for CPR. They may still take the patient to the hospital for other needed care, including comfort care to relieve pain and reduce suffering.

What happens to a DNR order issued in the hospital or nursing home if the patient is transferred from the hospital or nursing home to home care?

The orders issued for the patient in a hospital or nursing home may not apply at home. The patient or other decision maker must get a nonhospital DNR order on the DOH-3474 form or the DOH-5003 MOLST form. If the patient leaves the hospital or nursing home without a nonhospital DNR order, it can be issued by a doctor at home.

- For our patient directory, including to our chaplaincy services department, such as a priest or rabbi.
- With your family, friends, or others involved in your care or payment for your care.

In the following situations, we will only use or share your information if you give us written permission:

- For marketing purposes
- Sale of your information or payments from a third party
- Most sharing of psychotherapy notes
- Any other reasons not described in this Notice

You can revoke (take back) that permission, except when we have already relied on it, by contacting the Privacy Officer.

Your Rights

When it comes to your health information, you have certain rights. You may:

- Review or get an electronic or paper copy of your medical record, including billing records. You may be charged a reasonable cost based fee for your records. We will let you know about any delay. You can also access your health information directly using our secure patient portal, NYU Langone Health MyChart at https://mychart.nyulmc.org/.
- Request confidential communications. You can ask us to contact you in a certain way, for example, by cell phone. We will say "yes" to all reasonable requests.
- Ask us to limit what we use or share for your treatment, payment, and healthcare operations. We are not required to agree to your request, but we will review it. When you pay for services out-of-pocket, in full, and ask us not to share the information with your insurance plan, we will agree unless a law requires us to share that information.
- Ask us to correct your medical record if it is inaccurate or incomplete. We may say "no" to your request, but we will tell you why in writing within 60 days.
- Get a list of those with whom we have shared information. You can ask for a list (accounting) of the times we shared your information and why for the six years prior to your request. Not all disclosures will be included in this list, such as those made for treatment, payment, or health care operations. You have the right to get this list one time every 12 months without charge, but we may charge you for the cost of providing additional lists during that time.
- Get a copy of this privacy Notice. Just ask us and we will give you a copy in the format you would like (paper or electronic).
- Choose someone to act for you. This "personal representative" can exercise your rights and make choices about your health information. Generally, parents and guardians of minors will have this right for the child, unless the minor is permitted by law to act on their own behalf.
- File a complaint if you feel your rights have been violated. You may contact the Privacy Officer or the Secretary of the United States Department of Health and Human Services. We will not retaliate or take action against you for filing a complaint.
- Request additional privacy protections with respect to your electronic medical record.

Our Responsibilities

- We are required by law to maintain the privacy of your protected health information.
- We will notify you if a breach occurs that may have compromised the privacy or security of your identifiable information.
- We must follow the practices described in this Notice and give you a copy of it.
- We reserve the right to change the terms of this Notice and the changes will apply to all information we have about you. The new Notice will be available upon request and on our website at www.nyulangone.org.

Questions or Concerns

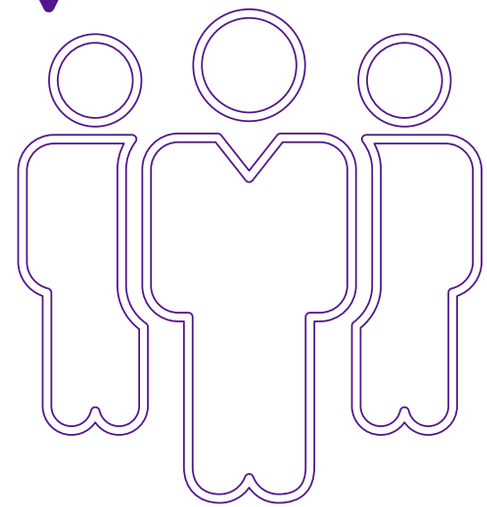
If you have a question or wish to exercise your rights described in this Notice, please contact the Privacy Officer at: One Park Avenue, 3rd Floor, New York, New York 10016, Attention: Privacy Officer, by phone to 1-877-PHI-LOSS or 212-404-4079, or via email to compliancehelp@nyulangone.org.

Most requests to exercise your rights must be made in writing to the Privacy Officer or the appropriate doctor's office or hospital department. For more information or to get a request form, contact the Privacy Officer or visit http://nyulangone.org/policies-disclaimers/hipaa-patient-privacy.

This Notice is effective as of 9/1/2022.

NYU Langone Health

NOTICE OF Privacy Practices



El Aviso sobre prácticas de privacidad también está disponible en español. Para recibir la versión en español de este aviso, solicite una copia en la mesa de registros.

Уведомление о соблюдении конфиденциальности доступно также на русском языке. Для получения копии этого уведомления, пожалуйста, обратитесь в приемное отделение.

私隱守則通知也有中文版本。要獲取該通知的中文版本，請於接待處索取。

דער מעלדונג פון פריוואטקייט פירונגען איז אויך אוועילעבל אין אידיש. צו באקומען די אידישע ווערסיע, פארלאנגט א קאפיע ביים פאציענט רעגיסטראציע טישל.

كما أن إخطار ممارسات الخصوصية متاح باللغة العربية. للحصول على نسخة باللغة العربية، اطلب نسخة من مكتب تسجيل المرضى.

Notis sou pratik sou lavi prive a disponib tou an kreyòl. Pou resevwa vèsyon an kreyòl la, ou ka mande yon kopi nan biwo anrejistreman malad la.

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

We are Committed to Your Privacy

NYU Langone Health is committed to maintaining the privacy and confidentiality of your health information. We will only use or disclose (share) your health information as described in this Notice. You will be asked to sign an acknowledgement that you have received this Notice.

Who Follows This Notice

This is a joint Notice that is followed by all employees, medical staff, trainees, students, volunteers, and agents of NYU Langone Health at these locations:

- NYU Langone Hospitals (including the NYU Langone Health Home Care)
- NYU Grossman School of Medicine (including our Faculty Group Practices)
- The Family Health Centers at NYU Langone Health
- Southwest Brooklyn Dental Practice
- Long Island Community Hospital ("LICH")

NYU Langone Hospitals and NYU Grossman School of Medicine participate in an Organized Health Care Arrangement ("OHCA") with the following entities:

- Family Health Centers at NYU Langone Health;
- The Southwest Brooklyn Dental Practice; and
- Long Island Community Hospital ("LICH")

Those entities participating in the OHCA may use and share between each other your information to carry out treatment, payment, and health care operations relating to this arrangement.

If NYU Langone Health professionals provide you with treatment or services at other locations, for example at the Manhattan VA Medical Center or Bellevue Hospital Center, the Notice of Privacy Practices you receive there will apply.

Using and Sharing Your Information

This section describes the different ways that we may use and share your information. We will usually contact you for these purposes by phone, but if you have given us your email address or permission to send a text message, we may contact you that way. .Communication by text message and email may be unsecure and unencrypted, and by providing us your mobile phone number or email, you authorize NYU Langone Health to communicate with you in this way.

We mainly use and share your information for treatment, payment, and health care operation purposes. This means we use and share your health information:

- with other health care providers who are treating you or with a pharmacy that is filling your prescription;
- with your insurance plan to collect payment for health care services or to get pre-approval for your treatment; and
- to run our business, improve your care, educate our professionals, and evaluate provider performance.

Sometimes we may share your information with our business associates, such as a billing service, who help us with our business operations. All of our business associates must protect the privacy and security of your health information just as we do.

We may also use or share your information to contact you:

- about health-related benefits or services.
- about your upcoming appointments.
- to see if you would like to take part in research projects.
- about fundraising for NYU Langone Health.

You have the right to opt out of receiving fundraising communications. You can do this by contacting the NYU Langone Health Development Office at developmentoffice@nyulangone.org or by phone at 212-404-3640 or, toll free, 1-800-422-4483.

If you do not wish to be notified of research projects you may be able to participate in, you can contact research-contact-optout@nyulangone.org or 1-855-777-7858.

Special protections apply if we use or share sensitive health information. This includes HIV-related information, mental health information, alcohol or drug abuse treatment information, or genetic information. For example, under New York State Law, confidential HIV-related information can only be shared with persons allowed to have it by law, or persons you have allowed to have it by signing a specific authorization form. If your treatment involves this information, you may contact the Privacy Officer for further explanation.

We are also allowed, and sometimes required by law, to share your information in other ways. We have to meet certain conditions in the law before we can share your information for the following reasons. Some examples of each include:

- Public health and safety: reporting diseases, births, or deaths; reporting suspected abuse, neglect, or domestic violence; to avoid a serious threat to health or public safety; monitoring product recalls; and reporting information for safety and quality purposes
- Research: analyzing health record projects that have been approved by our institutional review board (IRB) and are of low risk to your privacy; preparing for a research study; studies that only involve decedents' information
- Judicial and administrative proceedings: responding to a court or administrative order
- Workers' compensation and other government requests: workers' compensation claims payment or hearings; health oversight agencies for activities authorized by law; special government functions (military, national security)
- Law enforcement: with a law enforcement official to identify or find a suspect or missing person
- Comply with the law: to the Department of Health and Human Services to see if we are complying with federal privacy law
- Disaster relief situation: sharing your location and general location for the purpose of notifying your family, friends, and agencies chartered by law to assist in emergency situations
- To organizations that handle organ, tissue, or eye donation or transplantation
- To a coroner, medical examiner, or funeral director as needed to do their jobs
- Incidental to a permitted use or disclosure: calling your name in a waiting area for an appointment and others in the waiting area may hear your name called. We make reasonable efforts to limit these incidental uses and disclosures.

In the following situations, we may use or share your information, unless you object or if you specifically give us permission. If for some reason you are not able to tell us your preferences, for example if you are unconscious, we may share your information if we believe it is in your best interest.

Health Care Proxy

Appointing Your Health Care Agent in New York State

The New York Health Care Proxy Law allows you to appoint someone you trust — for example, a family member or close friend – to make health care decisions for you if you lose the ability to make decisions yourself. By appointing a health care agent, you can make sure that health care providers follow your wishes. Your agent can also decide how your wishes apply as your medical condition changes. Hospitals, doctors and other health care providers must follow your agent's decisions as if they were your own. You may give the person you select as your health care agent as little or as much authority as you want. You may allow your agent to make all health care decisions or only certain ones. You may also give your agent instructions that he or she has to follow. This form can also be used to document your wishes or instructions with regard to organ, eye and/or tissue donation.

About the Health Care Proxy Form

This is an important legal document. Before signing, you should understand the following facts:

1. This form gives the person you choose as your agent the authority to make all health care decisions for you, including the decision to remove or provide life-sustaining treatment, unless you say otherwise in this form. “Health care” means any treatment, service or procedure to diagnose or treat your physical or mental condition.
2. Unless your agent reasonably knows your wishes about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenous line), he or she will not be allowed to refuse or consent to those measures for you.
3. Your agent will start making decisions for you when your doctor determines that you are not able to make health care decisions for yourself.
4. You may write on this form examples of the types of treatments that you would not desire and/or those treatments that you want to make sure you receive. The instructions may be used to limit the decision-making power of the agent. Your agent must follow your instructions when making decisions for you.
5. You do not need a lawyer to fill out this form.
6. You may choose any adult (18 years of age or older), including a family member or close friend, to be your agent. If you select a doctor as your agent, he or she will have to choose between acting as your agent or as your attending doctor because a doctor cannot do both at the same time. Also, if you are a patient or resident of a hospital, nursing home or mental hygiene facility, there are special restrictions about naming someone who works for that facility as your agent. Ask staff at the facility to explain those restrictions.
7. Before appointing someone as your health care agent, discuss it with him or her to make sure that he or she is willing to act as your agent. Tell the person you choose that he or she will be your health care agent. Discuss your health care wishes and this form with your agent. Be sure to give him or her a signed copy. Your agent cannot be sued for health care decisions made in good faith.
8. If you have named your spouse as your health care agent and you later become divorced or legally separated, your former spouse can no longer be your agent by law, unless you state otherwise. If you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.
9. Even though you have signed this form, you have the right to make health care decisions for yourself as long as you are able to do so, and treatment cannot be given to you or stopped if you object, nor will your agent have any power to object.
10. You may cancel the authority given to your agent by telling him or her or your health care provider orally or in writing.
11. Appointing a health care agent is voluntary. No one can require you to appoint one.
12. You may express your wishes or instructions regarding organ, eye and/or tissue donation on this form.

Frequently Asked Questions

Why should I choose a health care agent?
If you become unable, even temporarily, to make health care decisions, someone else must decide for you. Health care providers often look to family members for guidance. Family members may express what they think your wishes are related to a particular treatment. Appointing an agent lets you control your medical treatment by:

- allowing your agent to make health care decisions on your behalf as you would want them decided;
- choosing one person to make health care decisions because you think that person would make the best decisions;
- choosing one person to avoid conflict or confusion among family members and/or significant others.

You may also appoint an alternate agent to take over if your first choice cannot make decisions for you.

Who can be a health care agent?
Anyone 18 years of age or older can be a health care agent. The person you are appointing as your agent or your alternate agent cannot sign as a witness on your Health Care Proxy form.

How do I appoint a health care agent?
All competent adults, 18 years of age or older, can appoint a health care agent by signing a form called a Health Care Proxy. You don't need a lawyer or a notary, just two adult witnesses. Your agent cannot sign as a witness. You can use the form printed here, but you don't have to use this form.

When would my health care agent begin to make health care decisions for me?
Your health care agent would begin to make health care decisions after your doctor decides that you are not able to make your own health care decisions. As long as you are able to make health care decisions for yourself, you will have the right to do so.

What decisions can my health care agent make?
Unless you limit your health care agent's authority, your agent will be able to make any health care decision that you could have made if you were able to decide for yourself. Your agent can agree that you should receive treatment, choose among different treatments and decide that treatments should not be provided, in accordance with your wishes and interests. However, your agent can only make decisions about artificial nutrition and hydration (nourishment and water provided by feeding tube or intravenous line) if he or she knows your wishes from what you have said or what you have written. The Health Care Proxy form does not give your agent the power to make non-health care decisions for you, such as financial decisions.

Why do I need to appoint a health care agent if I'm young and healthy?
Appointing a health care agent is a good idea even though you are not elderly or terminally ill. A health care agent can act on your behalf if you become even temporarily unable to make your own health care decisions (such as might occur if you are under general anesthesia or have become comatose because of an accident). When you again become able to make your own health care decisions, your health care agent will no longer be authorized to act.

How will my health care agent make decisions?
Your agent must follow your wishes, as well as your moral and religious beliefs. You may write instructions on your Health Care Proxy form or simply discuss them with your agent.

Frequently Asked Questions, *continued*

How will my health care agent know my wishes?
Having an open and frank discussion about your wishes with your health care agent will put him or her in a better position to serve your interests. If your agent does not know your wishes or beliefs, your agent is legally required to act in your best interest. Because this is a major responsibility for the person you appoint as your health care agent, you should have a discussion with the person about what types of treatments you would or would not want under different types of circumstances, such as:

- whether you would want life support initiated/continued/removed if you are in a permanent coma;
- whether you would want treatments initiated/continued/removed if you have a terminal illness;
- whether you would want artificial nutrition and hydration initiated/withheld or continued or withdrawn and under what types of circumstances.

Can my health care agent overrule my wishes or prior treatment instructions?
No. Your agent is obligated to make decisions based on your wishes. If you clearly expressed particular wishes, or gave particular treatment instructions, your agent has a duty to follow those wishes or instructions unless he or she has a good faith basis for believing that your wishes changed or do not apply to the circumstances.

Who will pay attention to my agent?
All hospitals, nursing homes, doctors and other health care providers are legally required to provide your health care agent with the same information that would be provided to you and to honor the decisions by your agent as if they were made by you. If a hospital or nursing home objects to some treatment options (such as removing certain treatment) they must tell you or your agent BEFORE or upon admission, if reasonably possible.

What if my health care agent is not available when decisions must be made?
You may appoint an alternate agent to decide for you if your health care agent is unavailable, unable or unwilling to act when decisions must be made. Otherwise, health care providers will make health care decisions for you that follow instructions you gave while you were still able to do so. Any instructions that you write on your Health Care Proxy form will guide health care providers under these circumstances.

What if I change my mind?
It is easy to cancel your Health Care Proxy, to change the person you have chosen as your health care agent or to change any instructions or limitations you have included on the form. Simply fill out a new form. In addition, you may indicate that your Health Care Proxy expires on a specified date or if certain events occur. Otherwise, the Health Care Proxy will be valid indefinitely. If you choose your spouse as your health care agent or as your alternate, and you get divorced or legally separated, the appointment is automatically cancelled. However, if you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.

Can my health care agent be legally liable for decisions made on my behalf?
No. Your health care agent will not be liable for health care decisions made in good faith on your behalf. Also, he or she cannot be held liable for costs of your care, just because he or she is your agent.

Frequently Asked Questions, *continued*

Is a Health Care Proxy the same as a living will?
No. A living will is a document that provides specific instructions about health care decisions. You may put such instructions on your Health Care Proxy form. The Health Care Proxy allows you to choose someone you trust to make health care decisions on your behalf. Unlike a living will, a Health Care Proxy does not require that you decide in advance decisions that may arise. Instead, your health care agent can interpret your wishes as medical circumstances change and can make decisions you could not have known would have to be made.

Where should I keep my Health Care Proxy form after it is signed?
Give a copy to your agent, your doctor, your attorney and any other family members or close friends you want. Keep a copy in your wallet or purse or with other important papers, but not in a location where no one can access it, like a safe deposit box. Bring a copy if you are admitted to the hospital, even for minor surgery, or if you undergo outpatient surgery.

May I use the Health Care Proxy form to express my wishes about organ, eye and/or tissue donation?
Yes. Use the optional organ, eye and/or tissue donation section on the Health Care Proxy form and be sure to have the section witnessed by two people. You may specify that your organs, eyes and/or tissues be used for transplantation, research or educational purposes. Any limitation(s) associated with your wishes should be noted in this section of the proxy. **Failure to include your wishes and instructions on your Health Care Proxy form will not be taken to mean that you do not want to be an organ, eye and/or tissue donor.**

Can my health care agent make decisions for me about organ, eye and/or tissue donation?
Yes. As of August 26, 2009, your health care agent is authorized to make decisions after your death, but only those regarding organ, eye and/or tissue donation. Your health care agent must make such decisions as noted on your Health Care Proxy form.

Who can consent to a donation if I choose not to state my wishes at this time?
It is important to note your wishes about organ, eye and/or tissue donation to your health care agent, or "health care proxy," family members, and the person responsible for disposition of your remains. If you have not already made your wishes to become, or not to become, an organ and/or tissue donor known, New York Law provides a list of individuals who are authorized to consent to organ, eye and/or tissue donation on your behalf. They are listed as follows, in order of priority: your health care agent/proxy; your spouse, if you are not legally separated, or your domestic partner; a son or daughter 18 years of age or older; either of your parents; a brother or sister 18 years of age or older; an adult grandchild; a grandparent; a guardian appointed for you by a court prior to your death; or any other person authorized to dispose of your body.

Health Care Proxy Form Instructions

Item (1)
Write the name, home address and telephone number of the person you are selecting as your agent.

Item (2)
If you want to appoint an alternate agent, write the name, home address and telephone number of the person you are selecting as your alternate agent.

Item (3)
Your Health Care Proxy will remain valid indefinitely unless you set an expiration date or condition for its expiration. This section is optional and should be filled in only if you want your Health Care Proxy to expire.

Item (4)
If you have special instructions for your agent, write them here. Also, if you wish to limit your agent's authority in any way, you may say so here or discuss them with your health care agent. If you do not state any limitations, your agent will be allowed to make all health care decisions that you could have made, including the decision to consent to or refuse life-sustaining treatment.

If you want to give your agent broad authority, you may do so right on the form. Simply write: I have discussed my wishes with my health care agent and alternate and they know my wishes including those about artificial nutrition and hydration.

If you wish to make more specific instructions, you could say:

If I become terminally ill, I do/don't want to receive the following types of treatments....

If I am in a coma or have little conscious understanding, with no hope of recovery, then I do/don't want the following types of treatments:....

If I have brain damage or a brain disease that makes me unable to recognize people or speak and there is no hope that my condition will improve, I do/don't want the following types of treatments:....

I have discussed with my agent my wishes about_____ and I want my agent to make all decisions about these measures.

Examples of medical treatments about which you may wish to give your agent special instructions are listed below. This is not a complete list:

- artificial respiration
- artificial nutrition and hydration (nourishment and water provided by feeding tube)
- cardiopulmonary resuscitation (CPR)
- antipsychotic medication
- electric shock therapy
- antibiotics
- surgical procedures
- dialysis
- transplantation
- blood transfusions
- abortion
- sterilization

Item (5)
You must date and sign this Health Care Proxy form. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure to include your address.

Item (6)
You may state wishes or instructions about organ, eye and /or tissue donation on this form. New York law does provide for certain individuals in order of priority to consent to an organ, eye and/or tissue donation on your behalf: your designated health care agent/ proxy; your designated agent to control the disposition of your remains; your spouse , if you are not legally separated, or your domestic partner; a son or daughter 18 years of age or older; either of your parents; a brother or sister 18 years of age or older; an adult grandchild; a grandparent; a guardian appointed by a court prior to your death; or any other person authorized to dispose of your body.

Item (7)
Two witnesses 18 years of age or older must sign this Health Care Proxy form. The person who is appointed your agent or alternate agent cannot sign as a witness.

Health Care Proxy

(1) I, _____

hereby appoint _____
(name, home address and telephone number)

_____

_____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint _____
(name, home address and telephone number)

_____

_____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (*Optional: If you want this proxy to expire, state the date or conditions here.)* This proxy shall expire *(specify date or conditions):*

_____

_____

(4) Optional: I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. *(If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.)* I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions *(attach additional pages as necessary):*

_____

_____

In order for your agent to make health care decisions for you about artificial nutrition and hydration *(nourishment and water provided by feeding tube and intravenous line),* your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) Your Identification *(please print)*

Your Name _____

Your Signature _____ Date _____

Your Address _____

(6) Optional: Organ, Eye and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of:
(check any that apply)

☐ Any needed organs, eyes and/or tissues

☐ The following organs, eyes and/or tissues _____

_____

☐ Limitations _____

If you do not state your wishes or instructions about organ, eye and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature _____ Date _____

(7) Statement by Witnesses *(Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)*

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1

Date _____

Name *(print)* _____

Signature _____

Address _____

_____

Witness 2

Date _____

Name *(print)* _____

Signature _____

Address _____

_____

Department of Health

NYU Langone Health

Advance Care Planning
for People of All Ages

PREPARING FOR LIFE'S "WHAT IFS"

Routine check-ups are part of great health care. So are open and honest conversations about what is important to you. Plan ahead and choose a trusted, reliable person to help make health care choices for you. This person will make decisions for you if you have a sudden event or illness that prevents you from doing so.

TALK ABOUT WHAT IS IMPORTANT

Explain what is important to you, such as your goals, values, and preferences. Let us know how these shape the decisions you make about your health care.

CHOOSE SOMEONE WHO CAN SPEAK FOR YOU

Choose a trusted, reliable person to make sure that your health care wishes are known and honored. This person will speak for you if you are ever temporarily or permanently unable to make decisions for yourself. This person is called a "health care agent." A health care agent can be a family member, spouse, same-sex or domestic partner, an adult child, a friend, or someone you trust. Your health care agent must be willing to accept this role. They will talk to you about your goals, values, preferences, and respect your decisions. Moreover, your health care agent will make decisions for you in difficult moments if needed.

DOCUMENT YOUR WISHES AND SHARE YOUR PLAN

Complete a health care proxy form, which is an "advance directive," and share it with your health care agent, doctor, hospital, and those you care about. When you document your wishes, it becomes an important way to make sure they are honored. It is also a vital part of advance care planning.

The Medical Orders for Life Sustaining Treatment (MOLST) form may be helpful if you have a serious health condition. The MOLST does not take the place of the "advanced directive." The MOLST helps you and your loved ones plan for health care decisions that may need to be made. This document may be needed in the event that you are not able to speak due to your serious illness. The MOLST form is signed by a doctor as a medical order and is valid in any health care setting, and at home.

LET YOUR HEALTHCARE AGENT MAKE DECISIONS FOR YOU WHEN NEEDED

Your health care agent would only begin to make health care decisions after your doctor decides you cannot do so. As long as you are able, you will have the right to make your own health care decisions.

UPDATE YOUR PLAN AT ANY TIME

Advance care planning is an ongoing process, not a one-time event; you can update your advance care plan at any time.

We understand that you may feel uncomfortable talking about these difficult topics. Starting the conversation is an important first step, which can make things easier in the future. If you plan ahead (at any age or health status), this will ensure your health care wishes are known. It is an important gift to yourself and to your loved ones.

QUESTIONS

For more information and for help with completing a health care proxy form or MOLST, ask your health care team or call the Advance Care Planning Program at 212-263-0416. For NYU Langone Orthopedic Hospital, call the Social Work Department at 212-598-6030. For NYU Langone Hospital—Brooklyn call the Social Work Department at 718-630-7515. For NYU Langone Hospital—Long Island, call the Social Work Department at 516-663-2341.

Patients' Bill of Rights in a Hospital

As a patient in a hospital in New York State, you have the right, consistent with law, to:

(1) Understand and use these rights. If for any reason you do not understand or you need help, the hospital MUST provide assistance, including an interpreter.

(2) Receive treatment without discrimination as to race, color, religion, sex, gender identity, national origin, disability, sexual orientation, age or source of payment.

(3) Receive considerate and respectful care in a clean and safe environment free of unnecessary restraints.

(4) Receive emergency care if you need it.

(5) Be informed of the name and position of the doctor who will be in charge of your care in the hospital.

(6) Know the names, positions and functions of any hospital staff involved in your care and refuse their treatment, examination or observation.

(7) Identify a caregiver who will be included in your discharge planning and sharing of post-discharge care information or instruction.

(8) Receive complete information about your diagnosis, treatment and prognosis.

(9) Receive all the information that you need to give informed consent for any proposed procedure or treatment. This information shall include the possible risks and benefits of the procedure or treatment.

(10) Receive all the information you need to give informed consent for an order not to resuscitate. You also have the right to designate an individual to give this consent for you if you are too ill to do so. If you would like additional information, please ask for a copy of the pamphlet "Deciding About Health Care — A Guide for Patients and Families."

(11) Refuse treatment and be told what effect this may have on your health.

(12) Refuse to take part in research. In deciding whether or not to participate, you have the right to a full explanation.

(13) Privacy while in the hospital and confidentiality of all information and records regarding your care.

(14) Participate in all decisions about your treatment and discharge from the hospital. The hospital must provide you with a written discharge plan and written description of how you can appeal your discharge.

(15) Review your medical record without charge and, obtain a copy of your medical record for which the hospital can charge a reasonable fee. You cannot be denied a copy solely because you cannot afford to pay.

(16) Receive an itemized bill and explanation of all charges.

(17) View a list of the hospital's standard charges for items and services and the health plans the hospital participates with.

(18) Challenge an unexpected bill through the Independent Dispute Resolution process.

(19) Complain without fear of reprisals about the care and services you are receiving and to have the hospital respond to you and if you request it, a written response. If you are not satisfied with the hospital's response, you can complain to the New York State Health Department. The hospital must provide you with the State Health Department telephone number.

(20) Authorize those family members and other adults who will be given priority to visit consistent with your ability to receive visitors.

(21) Make known your wishes in regard to anatomical gifts. Persons sixteen years of age or older may document their consent to donate their organs, eyes and/or tissues, upon their death, by enrolling in the NYS Donate Life Registry or by documenting their authorization for organ and/or tissue donation in writing in a number of ways (such as a health care proxy, will, donor card, or other signed paper). The health care proxy is available from the hospital.

Public Health Law(PHL)2803 (1)(g)Patient's Rights, 10NYCRR, 405.7,405.7(a)(1),405.7(c)

Parents' Bill of Rights

As a parent, legal guardian or person with decision-making authority for a pediatric patient receiving care in this hospital, you have the right, consistent with the law, to the following:

1) To inform the hospital of the name of your child's primary care provider, if known, and have this information documented in your child's medical record.

2) To be assured our hospital will only admit pediatric patients to the extent consistent with our hospital's ability to provide qualified staff, space and size appropriate equipment necessary for the unique needs of pediatric patients.

3) To allow at least one parent or guardian to remain with your child at all times, to the extent possible given your child's health and safety needs.

4) That all test results completed during your child's admission or emergency room visit be reviewed by a physician, physician assistant, or nurse practitioner who is familiar with your child's presenting condition.

5) For your child not to be discharged from our hospital or emergency room until any tests that could reasonably be expected to yield critical value results are reviewed by a physician, physician assistant, and/or nurse practitioner and communicated to you or other decision makers, and your child, if appropriate. Critical value results are results that suggest a life-threatening or otherwise significant condition that requires immediate medical attention.

6) For your child not to be discharged from our hospital or emergency room until you or your child, if appropriate, receives a written discharge plan, which will also be verbally communicated to you and your child or other medical decision makers. The written discharge plan will specifically identify any critical results of laboratory or other diagnostic tests ordered during your child's stay and will identify any other tests that have not yet been concluded.

7) To be provided critical value results and the discharge plan for your child in a manner that reasonably ensures that you, your child (if appropriate), or other medical decision makers understand the health information provided in order to make appropriate health decisions.

8) For your child's primary care provider, if known, to be provided all laboratory results of this hospitalization or emergency room visit.

9) To request information about the diagnosis or possible diagnoses that were considered during this episode of care and complications that could develop as well as information about any contact that was made with your child's primary care provider.

10) To be provided, upon discharge of your child from the hospital or emergency department, with a phone number that you can call for advice in the event that complications or questions arise concerning your child's condition.

Public Health Law (PHL) 2803(i)(g) Patients' Rights 10NYCRR, Section 405.7

NEW YORK STATE | Department of Health