



Your Rights

as a Hospital Patient
in New York State

Rights



Keep this booklet for reference.

Review it carefully and share the information with your family and friends involved in your care.

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The state and federal governments require that all hospital patients in New York State be given certain information and materials when admitted to a hospital. This booklet collects that information in one place, explains the rights of each hospital patient and contains advice for the patients on how best to get assistance.

The booklet is divided into two sections:

- The first section of this booklet explains the rights of each hospital patient in New York State. It also contains a Glossary to help understand terms commonly used in the hospital.
- The second section provides documents the law requires the hospital to provide to each patient while in a hospital in New York State.

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About Your Rights

As a patient in a New York State hospital, you have certain rights and protections guaranteed by state and federal laws and regulations. These laws and regulations help ensure the quality and safety of your hospital care. To help you understand your rights, the New York State Department of Health developed this booklet.

Keep this booklet for reference. Review it carefully and share the information with family and friends involved in your care.

You have the right to participate in decisions about your health care and to understand what you are being told about your care and treatment. For example, you are entitled to a clear explanation of tests, treatments and drugs prescribed for you. Don't hesitate to ask questions of your doctor, nurse or hospital staff members. **You have a right to know what's going on.**

Every patient is unique, every hospital stay is different. It is important to know what specific rights apply to you and what to do if you feel you need help. Some rights and protections, such as those that govern when you leave the hospital, depend on receiving correct written notices. You will also be provided with information explaining when and where to call or write for help.

If you have a problem or if you don't understand something, speak to your nurse, doctor, social worker or patient representative.

They can:

- help you get answers;
- arrange special help;
- make contacts with your family;
- get foreign language and sign language interpreters; and
- generally make your hospital stay easier.

About Your Special Needs

Each hospital must make staff available to explain or answer questions about your rights and to provide information on how you can protect those rights.

- If you are hearing or vision impaired, or if English is not your first language, skilled interpreters must be provided to assist you. Translations and/or transcriptions of important hospital forms, instructions and information must be provided to you if you feel you need them.

But you must speak up and ask questions.

You can contact a patient representative before you enter the hospital to be sure your special arrangements are made when you get there.

- If you have a question about any of the information in this booklet or feel that your needs have not been adequately met, ask the patient representative or other hospital staff person for further explanation or contact the New York State Department of Health (see page 3).

Concerns/Problems/Complaints About Your Hospital Care

If you have a concern, problem or complaint related to any aspect of care during your hospital stay, speak to your doctor, nurse or hospital staff member. If hospital staff has not resolved the problem, you may contact the New York State Department of Health by mail or phone.

You may call the toll-free number 1-800-804-5447 or you may file a complaint in writing and send it to:

New York State Department of Health
Centralized Hospital Intake Program
Mailstop: CA/DCS
Empire State Plaza
Albany, NY 12237

Questions or Comments: hospinfo@health.ny.gov

If You Think You Are Being Asked to Leave the Hospital Too Soon. . .

You have the right to appeal decisions made by your doctor, hospital staff or your managed care plan:

- about when you are to leave the hospital;
- if you feel you are being asked to leave the hospital too soon;
- if you believe you have not been given adequate or appropriate plans for your medical care and other services you may need after you leave the hospital; or
- if needed services are not in place.

The law requires that you receive advance notice **in writing** telling you:

- the date the physician and/or hospital plans to discharge you;
- how to appeal if you wish to remain in the hospital; and
- a special number to call with any problems related to leaving the hospital.

See page 14 for more information.

For Assistance/Help

There is an Independent Professional Review Agent (IPRA) for your area and your insurance coverage. Should you need assistance/help from the IPRA, the hospital will provide you with a phone number/person to contact. See page 9 and 15 for more information.

For Medicare Patients Only

If you feel that you are being asked to leave the hospital too soon and have not received advance notice telling you when to leave the hospital, ask for your discharge notice (called “The Important Message from Medicare about Your Rights”). If you are in a Healthcare Maintenance Organization (HMO), you should also request “The Important Message from Medicare about Your Rights”. You must have this written discharge notice in order to appeal the physician’s and hospital’s decision about when you are to leave. See an “Important Message from Medicare about Your Rights” on page 17 for a complete explanation.

For Managed Care Patients

If you are a patient enrolled in an HMO or managed care plan, first request/submit an expedited appeal to the HMO or plan’s utilization review committee if you feel your benefits are unfairly limited or denied, or you are being asked to leave the hospital too soon, or that medically necessary services are inappropriately excluded from your coverage. If you are not satisfied with the outcome of that appeal request, you may contact the New York State Department of Health by calling: **1-800-206-8125**.

The Managed Care Law of 1996 amending Public Health Law 4408, Disclosure of Information.

You Have the Right to File a Complaint About

• Doctors or Physician Assistants

If you feel that you have received incompetent, negligent or fraudulent care from a doctor or physician assistant, you may file a report with the New York State Department of Health Office of Professional Medical Conduct (OPMC). OPMC investigates all reports of possible professional misconduct by physicians and physician assistants. Reports must include the full name and address of the doctor or physician assistant and all relevant information. Reports must be made in writing to:

**New York State Department of Health
Office of Professional Medical Conduct
Intake Unit
Riverview Center
150 Broadway
Albany, NY 12204-2719**

For more information or to obtain a complaint form, call **1-800-663-6114** or visit the Department of Health website at www.health.ny.gov

Reports are kept confidential. An investigation may result in a formal hearing before a committee of the Board for Professional Medical Conduct. The Board consists of physicians and consumer members appointed by the Commissioner of Health.

See page 10 of the Glossary for examples of “medical misconduct” by a doctor or physician assistant.

• Other Health Care Professionals

If you feel you received incompetent, negligent or fraudulent care from any other licensed health care professionals, such as nurses, dentists, social workers, optometrists, psychologists, physical or occupational therapists and podiatrists, you may file a complaint by contacting:

**New York State Education Department
Office of Professional Discipline
475 Park Avenue South
2nd Floor
New York, New York 10016
1-800-442-8106**

Questions or Complaints About Your Hospital Bill or Health Insurance

- As a hospital patient, you are entitled to an itemized bill.
- Your hospital bill may identify a charge called a “surcharge.” These surcharges fund important public programs and have existed in previous years, although they may not have appeared as separate costs on the bill. The surcharge represents an additional amount due on total hospital bills in New York State and, depending on your insurance contract, New York State law allows a portion of these costs to be billed to you.
- Hospitals negotiate payment rates with insurers, HMOs and other types of managed care plans, as well as commercial insurers and self-insured groups. These rates may vary. Contact your insurer with any questions you may have regarding your coverage.

• If you have questions about your coverage, the services billed or amounts paid, contact the hospital’s billing office and your insurer to resolve any questions/problems that you may have.

For Medicare Patients

If you are a Medicare patient and have questions about your hospital bill, call Medicare:

1-800-MEDICARE (1-800-633-4227)

For Managed Care Patients

If you are enrolled in a managed care plan and you are having trouble getting care or feel your care is not satisfactory, you may complain to the plan. The plan’s handbook MUST tell you how to complain and how to get an immediate review. If you are not satisfied with the HMO or plan’s response to your complaint, contact the New York State Department of Health at:

1-800-206-8125

Medicare managed care enrollees may call Livanta:

1-866-815-5440

Access to Your Medical Records

New York State law requires all health care practitioners and facilities to grant patients access to their own medical records. Section 18 of the Public Health Law contains procedures for making these records available and the conditions under which a provider can deny access. Patients may request information, in writing, as may parents or guardians who have authorized their child's care.

If you **want to see** your medical records, ask your doctor and/or the director of medical records at the hospital. New York State law guarantees you the opportunity to inspect your medical records within 10 days of your written request.

If you **want to have a copy** of your medical records, you must submit a written request to the hospital. Address the request

to the Director of Medical Records at the hospital. If you request a copy of your records, the hospital may charge you up to 75 cents per page.

If the hospital **fails to acknowledge** or act on your request, you may complain to the Department of Health by calling 1-800-804-5447.

If you have been denied access to all or part of your hospital records, you may appeal to the New York State Department of Health Medical Records Access Review Committee. The hospital/doctor is required to provide a form (DOH-1989) that gives the reason(s) for denial and information on this appeals process.

Glossary

Advance Directives —

Advance directives are verbal or written instructions made by you before an incapacitating illness or injury (see page 18). Advance directives communicate that your wishes about your treatment be followed if you are too sick or unable to make decisions about your care. Advance directives include but are not limited to a **health care proxy**, a consent to a **do-not-resuscitate (DNR) order** recorded in your medical record and a **living will**.

Cardiopulmonary Resuscitation (CPR) —

CPR is a medical procedure used to restart a patient's heart and lungs when your breathing or circulation stops (see page 20).

Diagnosis Related Groups (DRGs) —

The diagnosis related group (DRG) system categorizes the entire range of reasons people are hospitalized into about 600 groups to determine how much the hospital will be paid by your insurance. The DRG system is based on the average cost of treating a patient within the same age range, diagnosed with the same or similar condition and needing the same type of treatment. For example, one amount is paid for patients with pneumonia and a different amount for patients with a broken hip. It takes into account a hospital's expenses, regional costs, inflation and patient needs. The New York State Department of Health has developed Medicaid and Workers Compensation/No Fault payments rates for each DRG within each hospital. **This does not limit the number of days a patient may stay in the hospital.** Your length of stay depends solely on your medical condition. (Note: Certain specialty units and facilities do not use DRGs.)

Discharge Notice —

A New York State hospital discharge notice should include information on your discharge date and how to appeal if you disagree with the notice. A discharge notice must be provided to all patients (except Medicare patients who receive a copy of an "Important Message from Medicare") **in writing** 24 hours before they leave the hospital. **Medicare patients must request a written discharge notice ("The Important Message from Medicare") if they disagree with discharge.** If requested, the notice must be provided. Once the notice is provided and if the Medicare patient disagrees with the notice, an appeal can be processed.

Discharge Plan —

All patients (including Medicare patients) in New York State hospitals must receive **a written discharge plan** before they leave the hospital. This plan should describe the arrangements for any health care services you may need after you leave the hospital. **The necessary services described in this plan must be secured or reasonably available before you leave the hospital.**

Discharge Planning —

Discharge planning is the process by which hospital staff work with you and your family or someone acting on your behalf to prepare and make arrangements for your care once you leave the hospital. This care may be self care, care by family members, home health assistance or admission to another health care facility. Discharge planning includes assessing and identifying what your needs will be when you leave the hospital and planning for appropriate care to meet those needs when you are discharged. **A plan must**

be provided to you in writing before you leave the hospital. Discharge planning usually involves the patient, family members or the person you designate to act on your behalf, your doctor and a member of the hospital staff. Some hospitals have staff members who are called “discharge planners.” In other hospitals, a nurse or social worker may assist in discharge planning.

Do-Not-Resuscitate (DNR) Order —

At your request, a DNR order may be included in your medical chart. It instructs the medical staff not to try to revive you if your breathing or heartbeat has stopped. This means that doctors, nurses and other health care practitioners will not initiate such emergency procedures as mouth-to-mouth resuscitation, external chest compression, electric shock, insertion of a tube to open your airway, injection of medication into your heart or open chest. Under New York State law, all adult patients can request a DNR order verbally or in writing if two witnesses are present. In addition, the Health Care Proxy Law allows you to appoint someone to make decisions about DNR and other treatments if you become unable to do so.

Health Care Proxy form —

New York State has a law that allows you to appoint someone you trust, for example, a family member or close friend as your Health Care Agent, to decide about your treatment if you lose the ability to decide for yourself. You may also use this form to indicate your wishes regarding organ donation in the event of your death (see page 23).

Independent Professional Review Agents (IPRA) —

These review agents handle appeals for patients covered by Medicaid, private insurance or those without any insurance if they are having problems getting the care they will need after discharge from the hospital. For example, an IPRA would review the medical records of patients who are discharged before they are medically ready, and if an appropriate discharge plan has not been done or if appropriate services were not in place.

Livanta —

This is the quality improvement organization contracted by the federal and state government to review the hospital’s care provided to Medicare patients in New York State.

- This is the agency Medicare patients should contact if they think they are being discharged too soon from the hospital. Patients with dual Medicare & Medicaid coverage may call Livanta toll free at 1-866-815-5440.
- If you have complaints about the quality of care you receive as a Medicare patient, call Livanta toll-free at 1-866-815-5440.
- TTY users should call 1-866-868-2289.
- Livanta provides translation services for all languages.

Island Peer Review Organization (IPRO) works with the New York State Department of Health to conduct the review of hospital care provided to people who are eligible for Medicaid. This is the agency Medicaid patients should contact if they think they are being discharged too soon from the hospital. Call toll-free at 1-800-648-4776, or 1-516-326-6131.

Living Will —

A living will is a written document that expresses in advance your specific instructions and choices about various types of medical treatments and certain medical conditions. Living wills may be recognized as evidence of your wishes (if such wishes are expressed in a clear and convincing manner) if you are seriously ill and not able to communicate.

Managed Care —

Managed care refers to the way an individual's (or family member's) health care is organized and paid for. While health maintenance organizations (HMOs) are the best known managed care plans, there are many other types. If you are enrolled in a managed care plan, your access to health care services is coordinated by the plan and/or primary care physician. Therefore, you should understand how, when and where to access health care services, including hospital services, according to your plan's rules and benefits. Read your plan's enrollment information carefully and ask questions of your plan representative to be sure you understand your benefits, rights and responsibilities.

Medicaid

(Title XIX of the Social Security Act) —

Medicaid is a federal program, financed by federal, state and local governments, intended to provide access to health care services for the poor, specifically those who meet certain eligibility requirements such as income level.

Medical Misconduct —

If you feel you have received poor or substandard care (incompetent, negligent or fraudulent care) from a doctor or physician assistant, you may file a report with the New York State Department of Health. Physicians and other health professionals are required by law to report any instance of suspected misconduct.

Some examples of medical misconduct are:

- practicing the profession fraudulently, or with gross incompetence or negligence;
- practicing while impaired by alcohol, drugs, physical disability or mental disability;
- being convicted of a crime;
- refusing to provide medical services because of race, creed, color or ethnic origin;
- guaranteeing that a cure will result from medical services;
- failing to make available to the patient or another physician, upon a patient's written request, copies of X-rays or medical records;
- willfully making or filing a false report, or failing to file a report required by law or inducing another person to do so;
- willfully harassing, abusing or intimidating a patient;
- ordering excessive tests or treatment;
- promoting the sale of services, goods, appliances or drugs in a manner that exploits the patient;
- abandoning or neglecting a patient under and in need of immediate professional care.

Medicare

(Title XVIII of the Social Security Act) —

Medicare is a federal program, administered by the federal government, which pays part of the costs of medical services for people aged 65 or older or who are disabled. Eligibility rests solely upon age or disability.

Patient Representative —

The patient representative is a member of the hospital staff who serves as a link between the patient, family, physicians and other hospital staff. The patient representative should be available to answer questions about hospital procedures, help with special needs or concerns and help solve problems. The patient representative is familiar with all hospital services and will assist you. There is no charge for services rendered by the patient representative.

Quality Improvement Organization

(QIO) —

QIOs are the agencies responsible for ongoing review of the inpatient hospital care provided to people who are eligible for Medicare. In New York State, the QIO is Livanta (see page 9).

Utilization Review —

Utilization review is a process where the need, appropriateness and effectiveness of care are evaluated. This is performed by a hospital utilization review (UR) committee, a Quality Improvement Organization (QIO) (see QIO), a public agency (health department, for example) or an independent organization.

Regulations and Information

This section presents each document that the law requires you receive as an inpatient in a hospital in New York State.

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Domestic Violence

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Information that must be provided before you leave the hospital:

- **All** patients must receive a written discharge plan.
- **Medicare** patients receive a copy of the "Important Message From Medicare".
- **All** other patients must receive a hospital discharge notice.

If you have trouble understanding anything or have any questions about these materials, ask the hospital staff for an explanation. It is your right!

Patients' Bill of Rights

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, national origin, disability, sexual orientation, source of payment, or age.
- (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) A no smoking room.
- (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. 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) 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.
- (18) Authorize those family members and other adults who will be given priority to visit consistent with your ability to receive visitors.
- (19) Make known your wishes in regard to anatomical gifts. You may document your wishes in your health care proxy or on a donor card, available from the hospital.

Important Message Regarding Your Rights as a Hospital Inpatient

Your Rights While a Hospital Patient

You have the right to receive all of the hospital care that you need for the treatment of your illness or injury. Your discharge date is determined only by **YOUR** health care needs, not by your DRG category or your insurance.

You have the right to be fully informed about decisions affecting your care and your insurance coverage. **ASK QUESTIONS.** You have the right to designate a representative to act on your behalf.

You have the right to know about your medical condition. Talk to your doctor about your condition and your health care needs. If you have questions or concerns about hospital services, your discharge date or your discharge plan, consult your doctor or a hospital representative (such as the nurse, social worker or discharge planner).

Before you are discharged you must receive a written DISCHARGE NOTICE and a written DISCHARGE PLAN. You and/or your representative have the right to be involved in your discharge planning.

You have the right to appeal the written discharge plan or notice you receive from the hospital.

If You Think You are Being Asked to Leave the Hospital Too Soon

Be sure you have received the written notice of discharge that the hospital must give you. You need this discharge notice in order to appeal.

This notice will say whom to call and how to appeal. To avoid extra charges you must call to appeal no later than your planned discharge date. If you miss this time you may still appeal. However, you may have to pay for your continued stay in the hospital, if you lose your appeal.

Discharge Plans

In addition to the right to appeal, you have the right to receive a written discharge plan that describes the arrangements for any future health care you may need after discharge. You may not be discharged until the services required in your written discharge plan are secured or determined by the hospital to be reasonably available. You also have the right to appeal this discharge plan.

Patients' Rights*

A general statement of your additional rights as a patient must be provided to you at this time.

For Assistance/Help

The independent Professional Review Agent (IPRA) for your area and your insurance coverage is:

to be provided by hospital

*This information is now included in this booklet.

Patients are provided with a notice of their rights regarding admission and discharge. Medicare patients will be given the "Hospital Admission Notice for Medicare Patients", and all other patients will be given "An Important Message Regarding Your Rights as a Hospital Inpatient."

Public Health Law 2803 (1) (g) Discharge Review

10NYCRR, 405.9 (b) (14) (i) and 405.9 (b) (14) (ii)

Patients (or appointed personal representatives) are provided with a written discharge notice and a copy of a discharge plan. Patients (or their representatives) must be given the opportunity to sign the documents and receive a copy of the signed documents.

10NYCRR, 405.9 (g) (1) and 405.9 (g) (3) (i)

Admission Notice for Medicare Patients

You have the following rights under the New York State law:

Before you are discharged, you must receive a written Discharge Plan. You or your representative have the right to be involved in your discharge planning.

Your written Discharge Plan must describe the arrangements for any future health care that you may need after discharge. You may not be discharged until the services required in your written Discharge Plan are secured or determined to be reasonably available.

If you do not agree with the Discharge Plan or believe the services are not reasonably available, you may call the New York State Health Department to investigate your complaint and the safety of your discharge. The hospital must provide you with the State Health Department's telephone number if you ask for it.

For important information about your rights as a Medicare patient, see "Important Message from Medicare," on the following page.

Patients are provided with a notice of their rights regarding admission and discharge. Medicare patients will be given "Hospital Admission Notice for Medicare Patients", and all other patients will be given "An Important Message Regarding Your Rights as a Hospital Inpatient"

Public Health Law 2803 (1) (g) Discharge Review

10NYCRR 405.9 (b) (14) (i) and 405.9 (b) (14) (ii)

Important Message from Medicare About Your Rights

AS A HOSPITAL INPATIENT, YOU HAVE THE RIGHT TO:

- Receive Medicare covered services. This includes medically necessary hospital services and services you may need after you are discharged, if ordered by your doctor. You have a right to know about these services, who will pay for them, and where you can get them.
- Be involved in any decisions about your hospital stay, and know who will pay for it.
- Report any concerns you have about discharge and the quality of care you receive to the Quality Improvement Organization (QIO) listed here Livanta 1-866-815-5440.

YOUR MEDICARE DISCHARGE RIGHTS

Planning For Your Discharge: During your hospital stay, the hospital staff will be working with you to prepare for your safe discharge and arrange for services you may need after you leave the hospital. When you no longer need inpatient hospital care, your doctor or the hospital staff will inform you of your planned discharge date.

If you think you are being discharged too soon:

- You can talk to the hospital staff, your doctor and your managed care plan (if you belong to one) about your concerns.
- You also have the right to an appeal, that is, a review of your case by a Quality Improvement Organization (QIO). The QIO is an outside reviewer hired by Medicare to look at your case to decide whether you are ready to leave the hospital.
 - **If you want to appeal, you must contact the QIO no later than your planned discharge date and before you leave the hospital.**
 - If you do this, you will not have to pay for the services you receive during the appeal (except for charges like copays and deductibles).
- If you do not appeal, but decide to stay in the hospital past your planned discharge date, you may have to pay for any services you receive after that date.
- **Step by step instructions for calling the QIO and filing an appeal are on page 2.**

To speak with someone at the hospital about this notice, call _____.

Please sign and date here to show you received this notice and understand your rights.

Signature of Patient or Representative

Date

STEPS TO APPEAL YOUR DISCHARGE

- **STEP 1:** You must contact the QIO no later than your planned discharge date and before you leave the hospital. If you do this, you will not have to pay for the services you receive during the appeal (except for charges like copays and deductibles).
 - Here is the contact information for the QIO:
Livanta
1-866-815-5440
 - You can file a request for an appeal any day of the week. **Once you speak to someone or leave a message, your appeal has begun.**
 - Ask the hospital if you need help contacting the QIO.
 - The name of this hospital is {Name of Hospital}.
- **STEP 2:** You will receive a detailed notice from the hospital or your Medicare Advantage or other Medicare managed care plan (if you belong to one) that explains the reasons they think you are ready to be discharged.
- **STEP 3:** The QIO will ask for your opinion. You or your representative need to be available to speak with the QIO, if requested. You or your representative may give the QIO a written statement, but you are not required to do so.
- **STEP 4:** The QIO will review your medical records and other important information about your case.
- **STEP 5:** The QIO will notify you of its decision within 1 day after it receives all necessary information.
 - If the QIO finds that you are not ready to be discharged, Medicare will continue to cover your hospital services.
 - If the QIO finds you are ready to be discharged, Medicare will continue to cover your services until noon of the day after the QIO notifies you of its decision.

IF YOU MISS THE DEADLINE TO APPEAL, YOU HAVE OTHER APPEAL RIGHTS:

- You can still ask the QIO or your plan (if you belong to one) for a review of your case:
 - If you have Original Medicare: Call the QIO listed above.
 - If you belong to a Medicare Advantage Plan or other Medicare managed care plan: Call your plan.
- If you stay in the hospital, the hospital may charge you for any services you receive after your planned discharge date.

For more information, call 1-800-MEDICARE (1-800-633-4227), or TTY: 1-877-486-2048.

Additional Information:

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-0692. The time required to complete this information collection is estimated to average 15 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850.

Deciding about Health Care: A Guide for Patients and Families

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 that 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: www.health.ny.gov/professionals/patients/health_care_proxy/index.htm.

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.

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.

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 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 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.

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

Frequently Asked Questions, *continued*

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.

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 know in advance all the 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

Frequently Asked Questions, *continued*

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 and/or tissue donation?

Yes. Use the optional organ and 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 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 and/or tissue donor.

Can my health care agent make decisions for me about organ 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 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 and/or tissue donation to your health care agent, the person designated as your decedent's agent, if one has been appointed, and your family members. New York Law provides a list of individuals who are authorized to consent to organ and/or tissue donation on your behalf. They are listed in order of priority: your health care agent; your decedent's agent; 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; or a guardian appointed by a court prior to the donor's death.

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 and /or tissue donation on this form. New York law does provide for certain individuals in order of priority to consent to an organ and/or tissue donation on your behalf: your health care agent, your decedent's agent, 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, a guardian appointed by a court prior to the donor's death.

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 and/or Tissue Donation

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

Any needed organs and/or tissues

The following organs and/or tissues _____

Limitations _____

If you do not state your wishes or instructions about organ 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.

Date _____ Date _____

Name of Witness 1 *(print)* _____ Name of Witness 2 *(print)* _____

Signature _____ Signature _____

Address _____ Address _____



Department of Health

Statewide Planning and Research Cooperative System (SPARCS)

This is to notify all hospital patients that the New York State Department of Health has developed a statewide data system known as the Statewide Planning and Research Cooperative System (SPARCS) and that all acute care hospitals are required to submit to SPARCS certain billing and medical record information for all patients. This information in SPARCS will be used for financial studies, rate setting, utilization review, health planning, epidemiology and research studies.

Please be assured that under this program:

1. The New York State Department of Health will not receive the name of any patient or any information which will enable a patient to be identified within the SPARCS system.
2. Regulations have been enacted protecting a patient's privacy and confidentiality by restricting access to any sensitive information in SPARCS and assuring review of all requests by an independent public review board.
3. Regulations have been enacted protecting a patient's privacy and confidentiality by restricting access to any sensitive information in SPARCS and assuring review of all requests by the Data Governance Committee.
4. SPARCS is not designed to identify specific patients; instead it is structured to provide information on patterns of illnesses and costs of care in hospitals.

This hospital is required to submit patient medical record and billing data to the Department of Health pursuant to Section 400.18 of Article 1, Subchapter A, Chapter V, Title 10 (Health) of the OFFICIAL COMPILATION OF CODES, RULES AND REGULATIONS OF THE STATE OF NEW YORK. The privacy, confidentiality and security of the information supplied is protected pursuant to Section 400.18(e) of Article 1, Subchapter A, Chapter V, Title 10 (Health) of the OFFICIAL COMPILATION OF CODES, RULES AND REGULATIONS OF THE STATE OF NEW YORK.

For further information concerning SPARCS, please contact:

SPARCS Operations
Bureau of Health Informatics
Office of Quality and Patient Safety
New York State Department of Health
Empire State Plaza
Corning Tower, Room 878
Albany, New York 12237

Phone: (518) 473-8144

Fax: (518) 486-3518

Questions/Comments:
sparcs.submissions@health.ny.gov

Data Requests:
sparcs.requests@health.ny.gov

Hospitals must provide patients with a notification letter from the New York State Department of Health that relates to the statewide data collection system known as SPARCS

10NYCRR, 400.18 (b) (2) and (C) (2) (SPARCS Letter)

Maternity Information

Hospitals (and birth centers) must provide prospective maternity patients (at the time of prebooking) and the general public, upon request, with written information that includes statistics specific to each hospital's maternity-related procedures and practices, insurance coverage, and postpartum events.

This written information can help you to better understand what you can expect, learn more about your childbirth choices, plan for your baby's birth and prepare for postpartum recovery. It will also direct you to appropriate sources to obtain further information.

- **Hospital-specific statistics** will give you the percentages regarding deliveries and use of special procedures during births occurring at your hospital of choice. You will also be informed of the hospital's special practices, including the availability of birthing rooms or rooming in. This information is important to the planning of your childbirth experience.
- **Inpatient insurance coverage** in New York State is provided for a mother and her newborn for at least 48 hours after childbirth for vaginal delivery and at least 96 hours after a caesarean section. In addition, each hospital must provide patient education, assistance and training in breast or bottlefeeding and any necessary maternal or newborn clinical assessments. Check with your insurance company for more details on your maternity coverage.

- **Maternal depression or baby blues** may occur after giving birth. Your body has undergone physical and hormonal changes, which may leave you with feelings of sadness, mood swings, anger, anxiety and low self-esteem, for days or weeks following birth. The baby blues are very common and will pass in time. Your doctor can suggest some ways to help you feel better. Less common is maternal depression. The symptoms are severe and can include feelings of hopelessness, high anxiety, eating problems, feeling "out of control," and thoughts of harming yourself or the baby. Contact your doctor regarding these symptoms, as maternal depression is treatable. Your doctor must be contacted immediately if you feel as though you may hurt yourself or your baby.
- **Shaken baby syndrome** refers to the injuries that result from the violent shaking of an infant or child. New parents need to be aware of the danger of shaking their infant or small child. Often, a frustrated caregiver loses control and shakes an infant in an attempt to stop the baby from crying. Usually, there is no intent to harm the child, just to have the baby stop crying. The stress of caring for a newborn can place any caregiver, including parents, at risk for shaking a baby. For more information about shaken baby syndrome, visit the Department of Health website at www.health.ny.gov/prevention/injury_prevention/shaken_baby_syndrome/

Hospitals must also (1) assure that prenatal childbirth education classes are available for all prebooked women; (2) distribute newborn screening educational literature; (3) provide all prebooked women with a written description of available options for labor, delivery and postpartum services.

Public Health Law 2803-j Maternity patients information leaflet

10NYCRR, 405.21 (c), 405.21 (c) (8)

Notice for Prenatal and Maternity Patients

This notice contains information that will be valuable to you if you are a victim of domestic violence. If you are a victim of domestic violence you should request to speak with someone about your situation and be given this information in a private and confidential manner. Your rights as a patient will be violated if hospital staff asks if you are a victim of domestic violence in front of any accompanying partner or family member.

Are You And Your Baby Safe?

You might not be, if there is domestic violence in your life. Here are some questions to help you know if you're being abused:

Does your partner hurt you with words?

Does he insult you and make you feel worthless?

Does he put you down in front of other people?

Does he hurt you physically?

Does he push, slap, hit, punch, kick, choke or beat you?

Does he make you do sexual things you don't want to do or hurt you during sex?

Is he in charge of everything?

Does he tell you who you can and cannot see or talk to?

Does he control all the family's money?

Does he scare you?

Does he lose his temper, get very jealous or break things?

Does he threaten to hurt you, the kids, pets or himself?

Victims of domestic abuse are not always physically hurt. If you answered "yes" to any of the questions above, you might be abused. You or your children could be in danger.

You are not alone.

You are not to blame.

You do not deserve to be abused.

Did you know that domestic violence sometimes starts or gets worse during pregnancy?

And you're not the only one getting hurt:

- A woman who is abused during pregnancy may be more likely to have a miscarriage, infections, bleeding, anemia and other health problems. These can affect both her and her baby.
- She is twice as likely to have a low birthweight baby.
- Most men who hit their partners also beat their children. Some also sexually abuse children.
- Kids whose fathers beat their mothers can suffer from health problems, sleep problems, anger, guilt, fear and anxiety.
- Each year, more than 1,000 children in the U.S. die from injuries caused by their parents, guardians or others.

You and your baby do not deserve to be treated this way.

You have a right to be safe.

Help is available.

What type of help do you need? The services listed below are available in most communities. Anything you say is confidential.

- **Hotlines:** a counselor will talk to you on the phone and give you information, or just listen. She or he will also tell you places near you to call or go to for more help, if you want it. Hotline numbers are listed below.
- **Support groups:** you can talk with other women who have gone through what you're going through (a support group). It can help you feel less alone and you can share ideas and information on safety.
- **Services for children:** many programs have counseling and support for kids to help them understand what is happening. It gives them a chance to talk about their feelings.
- **Advocacy and other support services:** someone can help you through the "system." This person is a domestic violence advocate. Advocacy services often include help finding legal advice, counseling, health care, housing, a job and social services.

- **Police and the courts:** police can help in many ways, such as getting you and your children to a safe place in an emergency. Family and criminal courts can help by issuing an order of protection or by deciding custody, visitation or child support.
- **Shelters:** most counties have shelters and safe homes where you and your children can stay. Shelters can help you get many of the services listed above.

You are important.

No woman deserves to be abused.

No one "asks for it," and no one should have to live in fear. You owe it to your children to keep them — and yourself — safe.

You are not alone.

Help is available.

New York State Hotlines

Adult Domestic Violence:

(24 hours, 7 days a week)

English 1-800-942-6906

Spanish 1-800-942-6908

National Committee

to Prevent Child Abuse: 1-800-342-7472

Prevention information
and parent help-line

Office of Children

& Family Services 1-800-342-3720

To report child abuse

Domestic Violence Victim's Rights Notice

The Victim's Rights Notice was prepared to inform victims of domestic violence, of their legal rights and remedies available under the law. If you are a victim of domestic violence you are encouraged to request to speak privately with a social worker or someone who can help you. You should be interviewed privately out of eyesight or earshot of anyone who accompanies you. Your rights as a patient will be violated if hospital staff asks if you are a victim of domestic violence in front of any accompanying partner or family member.

If you are the victim of domestic violence:

The police can help you:

- get to a safe place away from the violence.
- get information on how the court can help protect you against the violence.
- get medical care for injuries you or your children may have;
- get necessary belongings from your home for you and your children;
- get copies of police reports about the violence;
- file a complaint in criminal court, and tell you where your local criminal and family courts are located.

The courts can help:

- If the person who harmed or threatened you is a family member or someone you've had a child with, then you have the right to take your case to the

criminal courts, the family court or both.

- If you and the abuser aren't related, weren't ever married or don't have a child in common, then your case can be heard only in the criminal court.
- The forms you need are available from the family court and the criminal court.
- The courts can decide to provide a temporary order of protection for you, your children and any witnesses who may request one.
- The family court may appoint a lawyer to help you in court if it is found that you cannot afford one.
- The family court may order temporary child support and temporary custody of your children.

New York Law States: "If you are the victim of domestic violence, you may request that the officer assist in providing for your safety and that of your children, including providing information on how to obtain a temporary order of protection. You may also request that the officer assist you in obtaining your essential personal effects and locating and taking you, or assist in making arrangements to take you and your children to a safe place within such officer's jurisdiction, including but not limited to a domestic violence program, a family member's or a friend's residence, or a similar place of safety. When the officer's jurisdiction is more than a single county, you may ask the officer to take you or make arrangements to take you and your children to a place of safety in the county where the incident occurred. If you or your children are in need of medical treatment, you have the right to request that the officer assist you in obtaining such medical treatment.

You may request a copy of any incident reports at no cost from the law enforcement agency.”

“You have the right to seek legal counsel of your own choosing and if you proceed in family court and if it is determined that you cannot afford an attorney, one must be appointed to represent you without cost to you. You may ask the district attorney or a law enforcement officer to file a criminal complaint. You also have the right to file a petition in the family court when a family offense has been committed against you. You have the right to have your petition and request for an order of protection filed on the same day you appear in court, and such request must be heard that same day or the next day court is in session. Either court may issue an order of protection from conduct constituting a family offense which could include, among other provisions, an order for the respondent or defendant to stay away from you and your children. The family court may also order the payment of temporary child support and award temporary custody of your children. If the family court is not in session, you may seek immediate assistance from the criminal

court in obtaining an order of protection. The forms you need to obtain an order of protection are available from the family court and the local criminal court. The resources available in this community for information relating to domestic violence, treatment of injuries, and places of safety and shelters can be accessed by calling the following 800 numbers. Filing a criminal complaint or a family court petition containing allegations that are knowingly false is a crime.”

**Get Help Now
Get Safe
Stay Safe**

Call:

1-800-942-6906 (English)
(24 hours)

or

1-800-942-6908 (Spanish)

or call your local
Domestic Violence Program

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



**Department
of Health**



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