Ethical Care; Patient Rights and Responsibilities, Ethics Committees, Advance Directives, Consent for Treatment

The Patients' Bill of Rights

The purpose of the Patients' Bill of Rights is to promote and assure healthcare quality and value, and support consumers and workers in the healthcare system. The seven areas of rights and responsibilities in the Bill of Rights are:

1. Information disclosure
2. Choice of providers and plans
3. Access to emergency services
4. Participation in treatment decisions
5. Respect and nondiscrimination
6. Confidentiality of health information
7. Complaints and appeals

The seven areas of rights and responsibilities in the Bill of Rights are:

1. Information disclosure
Patients have the right to receive accurate and easily understood information about their health plan, the healthcare professionals, and facilities. If patients speak another language, have a physical or mental disability, or do not understand something, assistance will be provided to help them make informed healthcare decisions.

2. Choice of providers and plans
Patients have the right to a choice of healthcare providers that so that they have access to appropriate high-quality health care.

3. Access to emergency services
Patients who have severe pain, injury, or sudden illness that convinces them that their health is in serious jeopardy, have the right to receive emergency services for screening and stabilization whenever and wherever needed, without prior authorization or financial penalty.

4. Participation in treatment decisions
Patients have the right to know treatment options and to participate in decisions about their care. Parents, guardians, family members, or other individuals can represent patients if they cannot make their own decisions.

5. Respect and nondiscrimination
Patients have a right to considerate, respectful and nondiscriminatory care from their doctors, health plan representatives, and other healthcare providers.

6. Confidentiality of health information
Patients have the right to talk in confidence with healthcare providers and to have their healthcare information protected. They also have the right to review and copy their own medical records and request that their physician amend their records in the case of error or misunderstanding.

7. Complaints and appeals
Patients have the right to a fair, fast, and objective review of differences with their health

plan, doctors, other personnel, or the hospital. This includes complaints about waiting times, operating hours, the conduct of healthcare personnel, and the adequacy of healthcare facilities.

Patient Responsibilities

Patients have rights, but they also have responsibilities. When they enter the healthcare system, they are entering into an agreement that is two-sided. Patients have the right to expect the healthcare system to do its best for them. Patients must also do their best to help the healthcare system provide what is best for them.

Patient Responsibilities include:

- Providing accurate and complete information to the best of their knowledge about their present conditions, past illnesses, hospitalizations, and medications
- Sharing concerns and asking for information when they do not understand something
- Complying with instructions and treatment plans developed with their healthcare teams
- Accepting responsibility for outcomes if treatment is refused or instructions are not followed
- Being aware of financial obligations and understanding the requirements of their insurance carriers and the limitations of their insurance policies
- Complying with the rules and regulations of the organization
- Being considerate of the rights of others.

Your role in helping patients to meet their responsibilities
Although patients have responsibilities, the organization also has an obligation to help them understand and meet their responsibilities. There are several ways healthcare workers do this:

- You must be sure patients understand that giving the facility false or incomplete information may result in inaccurate care and could be harmful. For example, if a patient has a history of using drugs and does not share that information, the patient might receive inadequate or incorrect anesthesia or pain medication.
- You must do whatever is necessary to make patients understand everything they need to know about their care, their condition, and their instructions for treatment.
- You must be sure patients understand the consequences of refusing treatment or not following instructions. Although they have the right to do so at any time, they must be aware that refusing treatment continually negates the reason for being in the hospital.
- You must provide patients with full explanations of recommended treatments, reasons for giving treatments, potential benefits of receiving treatments, and risks of refusing treatments. For example, if cancer patients refuse to accept chemotherapy treatments, they must be made to realize that although there are risks associated with treatment, there are also risks associated with not accepting treatment and the disease may progress without it.
- You must let patients know that they have to provide accurate information about insurance coverage and determine if they understand the limits of their policies. They must be made aware that they are responsible for procedures not covered by their insurance company.
- You may not only have to inform patients and their visitors of hospital rules and regulations, but you may also have to enforce the rules and regulations. For example, visitors may have to be told that visiting hours are over and they must leave the hospital.
- You may have to tell patients that they must respect the rights of other patients. For example, if they are playing music too loudly and it is disturbing others, you may have to tell them to lower the volume.

The Ethics Committee

A dilemma is usually an instance in which an undesirable or unpleasant choice must be made. An ethical dilemma occurs when two principles of ethics "collide."

For example, an ethical dilemma may arise if a patient refuses chemotherapy against physician's advice. Does the physician continue to care for the patient when he believes that continuing on this course will lead to harm for that patient? The conflict arises between the patient's right of autonomy and the physician's duty of beneficence - always to do what is best for the health of the patient.

An ethics committee deals with conflicts on principles of ethics. Your organization will have a policy or procedure for convening the Ethics Committee to discuss ethical dilemmas. The committee will listen to and discuss the problem, and provide recommendations. In most facilities, anyone can ask for an ethics consultation.

Consent for Treatment

What does "informed" consent mean?
Informed consent is a process in which consent is obtained for a treatment or healthcare service when the patient knows about and understands the treatment, including its implications, benefits and risks, and the alternatives. The patient must know they have the right to accept or refuse the treatment or service.

Before undergoing treatment, patients must give consent. Some patients may not be capable of giving consent because of their age, mental competence, or other possible factors. In a situation in which the patient cannot give consent, a guardian represents that patient. The designated guardian may be a parent, other relative, friend, or caregiver. Healthcare workers must ensure that the consent is "informed" and signed by either the patient or the guardian.

The Patient's Bill of Rights supports the right of patients to have information that they can understand. to know all treatment options, and to participate in the decision-making process.

Consent is a legal process and it is usually represented as a written document. It is illegal to proceed with treatment or surgery without informed consent. If a patient refuses treatment, the physician should be informed.

Process for obtaining consent
The process for obtaining consent involves knowing about:

- When consent must be obtained
- When consent does not need to be obtained
- What must be written on the consent form
- Who must sign the consent form.

<u>When consent must be obtained</u>
Consent is obtained when a patient is admitted. This consent gives permission for your organization to treat the patient represented on the consent form. Invasive treatments, such as surgery, require an additional consent form.

<u>When consent does not need to be obtained</u>
In an emergency, where life or limb is threatened, informed consent may not be necessary, unless the practitioner has reasonable knowledge that the patient would ordinarily refuse the treatment or procedure. If the practitioner knows that a patient needs a blood transfusion, but belongs to a religious group that does not condone blood transfusions, the physician cannot give the blood transfusion without informed consent.

What must be written on the consent form
The consent form is a legal document that states the procedure to be performed, alternatives, and any risks involved. The form must be written in language the patient understands. Medical terms must be clarified. For example, 'appendectomy' might be written as 'operation to remove appendix'.

Who must sign the consent form
The **patient** signs the consent form. If incapable of signing, the patient may be represented by a **guardian**. At the time of signing, the person signing must be mentally competent and able to understand the form. Patients should not sign a consent form if they are sedated or not fully awake and aware. Awareness can be assessed using the 'oriented x3' tool. Oriented x 3 means determination of orientation to time, person, and place. Questions are asked to determine if the patient knows who and where they are, and knowledge of day of week and time of day. The **witness** signs the form to witness the patient's or the guardian's signature. The witness is someone who is not directly involved in the procedure or treatment. The witness may be a nurse on the nursing unit, or admitting personnel in the Outpatient/Admitting area.

Rights and responsibilities in informed consent
There are two aspects to rights and responsibilities in informed consent:

1. Patient's right to information and choices
2. Healthcare workers' responsibilities in the consent process

The physician, nurse practitioner, physician assistant, or other designated person must explain the procedure, expected benefits, alternatives to the procedure and the risks. The treatment or procedure is fully discussed, and the patient is given the opportunity to ask questions and make decisions.

Signing a consent form must be a voluntary process. After signing the consent, patients still have the right to refuse a treatment or procedure.

Health care workers must know their responsibilities in the consent process and must support the Patients' Bill of Rights and the ethical principles in healthcare. Their responsibilities in the consent process are crucial to the patient's treatment, procedures, and healthcare services.

The physician, nurse practitioner, physician assistant, or designated person is responsible for explaining the procedure, its implications, expected benefits and risks, and alternatives to the procedure. The treatment or procedure must be discussed fully to satisfy the patient's or guardian's needs. The patient must be given the opportunity to ask questions and make decisions.

The witness should ask questions to verify that the patient or guardian understands the procedure. The witness is NOT responsible for explaining the procedure or treatment. If the witness determines that the person signing the consent does not understand the form or the procedure, the witness MUST NOT allow the form to be signed and must notify the person who will be doing the procedure. If the patient or guardian signs the form with an "x", the witness must document the reason why the signature is an "x".

Advance Directives

What are "advance directives?"
Recent advances in healthcare have resulted in extended life expectancies. However, some people DO NOT want an extended life if the quality of that life would be severely diminished. To enable people to indicate their wishes for future healthcare **before** they become incapacitated, an "advance directive" may be written.

The Patient Self-Determination Act of 1990 dictates that all patients entering the healthcare system (including home health, nursing homes, hospitals, etc.) must be given the opportunity to complete an advance directive document and have it on file. The document defines the patients' preferences in end-of-life decisions or at any time that they are unable to convey their own wishes regarding healthcare. Advance directives are **voluntary** and are supported by the Patient's Bill of Rights (item 4).

There are two types of advance directives:

- Living Wills
- Healthcare surrogates

Living Wills
Living Wills give direction about medical care, or limitations to medical care, that patients desire when there is no hope of recovery and they are unable to make their needs known.

Healthcare surrogates
Healthcare surrogates are persons who have the legal right to direct the care of patients who are unable to make informed decisions.

Each state has its own laws pertaining to advance directives, but they are similar in all states. An advance directive signed in one state will be honored in another.

Patients entering hospital should be told about advance directives and, if they do not have one, they should be provided with the opportunity to complete one. Patients should also be informed that advance directives may be changed (by the patient) at any time. If patients complete advance directives or have already prepared advance directives, copies must be placed in their charts and staff must be made aware of them. Patients must understand the importance of providing copies to families, doctors, healthcare surrogates and hospitals so their wishes are honored. Advance directives are NOT intended to be secret documents.

What is a "Living Will?"
A "Living Will" is a document that gives direction about the medical care, and limitations of medical care, desired by the patient when he or she is either in a permanent vegetative state with no hope of recovery or has an imminently terminal condition AND is unable to make his or her needs known (for example, if the patient is in a coma or otherwise unconscious or in a confused state). Living Wills have to be witnessed by two people or notarized, but they do not have to be drawn up by an attorney.

Patients must understand that they will be treated, will receive palliative care, and will be kept comfortable even when a Living Will is activated. Each state has its own requirements as to the type of care that can be designated. Some states allow the patient to say exactly what he or she does or does not want; others have limitations. A Living Will may include specifics such as whether to allow or withhold:

- Mechanical ventilation
- Cardio-pulmonary resuscitation (CPR)
- Nutrition, fluids, or feeding tubes
- Medication
- Other treatments.

Each state has its own requirements as to when a Living Will is applicable. As a rule, two physicians must certify that the patient meets the criteria before a Living Will can be enacted.

Important note: A Living Will is NOT the same as a "Do Not Resuscitate" order.

A "Do Not Resuscitate" order (also known as a "no-code" order) is written expressly to indicate the patient's request not to perform CPR if he or she stops breathing or has no pulse. Patients sometimes think that because they have a Living Will, they will automatically have a "Do Not Resuscitate" order (no-code). However, even with a Living Will, the law requires that a no-code order be written by a doctor. The doctor is the person who decides when to activate the Living Will, NOT the patient. The information in the Living Will is considered a guide for the doctor to use when faced with making the decision to write a no-code order. Some doctors are reluctant to do so. Patients must understand that a Living Will must be discussed thoroughly with both the family and the doctor so the patients' wishes are clearly understood and the desired no-code order will be written at the appropriate time.

What is a "healthcare surrogate?"
A "healthcare surrogate" (sometimes called a "healthcare representative" or "healthcare proxy") is the person or persons who can legally direct the care of a patient when he or she is unable to make informed decisions because of confusion, unconsciousness, etc. The "durable power of attorney for healthcare" form identifies this person or persons.

A healthcare surrogate's responsibilities include:

- Making decisions the patient would normally make concerning healthcare if he or she were able
- Carrying out the wishes of the patient (even though he or she may not agree with them).

Patients must be able to trust healthcare surrogates to carry out their wishes. A healthcare surrogate is responsible for making sure the contents of a Living Will are carried out according to the directions of the patient. However, the role of surrogates also includes representing patients **at any time** that they are unable to speak for themselves, not only when there is no hope of recovery.

Patients must be made aware of the importance of choosing the right healthcare surrogate. They must share with their surrogates all information regarding their wishes for future healthcare AND the contents of their Living Wills.

End of Patient Rights Lesson