Patient Bill of Rights

- To safe, considerate and respectful care, provided in a manner consistent with your beliefs;
- To expect that all communications and records pertaining to your care will be treated as confidential to the extent permitted by law;
- To know the physician responsible for coordinating your care at the Clinical Center;
- To receive complete information about diagnosis, treatment, and prognosis from the physician, in terms that are easily understood. If it is medically inadvisable to give such information to you, it will be given to a legally authorized representative;
- To receive information necessary for you to give informed consent prior to any procedure or treatment, including a description of the procedure or treatment, any potential risks or benefits, the probable duration of any incapacitation, and any alternatives. Exceptions will be made in the case of an emergency;
- To receive routine services when hospitalized at the Clinical Center in connection with your protocol. Complicating chronic conditions will be noted, reported to you, and treated as necessary without the assumption of long-term responsibility for their management;
- To know in advance what appointment times and physicians are available and where to go for continuity of care provided by the Clinical Center;
- To receive appropriate assessment of, and treatment for, pain;
- To refuse to participate in research, to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of these actions, including possible dismissal from the study and discharge from the Clinical Center. If discharge would jeopardize your health, you have the right to remain under Clinical Center care until discharge or transfer is medically advisable;
- To be transferred to another facility when your participation in the Clinical Center study is terminated;
- To expect that a medical summary from the Clinical Center will be sent to your referring physician;
- To designate additional physicians or organizations at any time to receive medical updates.

Your rights and safety are protected by procedures that provide an awareness of your medical choices, of any risks or benefits, and of possible consequences of participating in research. The list summarizes your rights as a research participant at the Clinical Center.

If you have questions about your rights, you may contact the Clinical Center patient representative at 301-496-2626.

The Laws that Protect Patients

The Federal and state governments have designed the patient's bill of rights. It is an important right called "informed consent." It means the patient has the right to gather information on the state of their health, ask questions about their treatment options, and make an informed decision, even if it goes against their provider's recommendation.

Other examples of federal laws include:

Health Insurance Portability and Accountability Act (HIPAA)

Legislators passed HIPAA in 1996 so individuals could get copies of their medical records and other health information. HIPAA also allows you to change incorrect information on your records and learn who else has seen your records besides your provider.

Pre-existing conditions under the Affordable Care Act (ACA)

This law under the ACA protects you from being denied health insurance or charged more if you have a pre-existing condition — a health problem you had before the start date of your health plan.

References

American Hospital Association. (n.d.). AHA.

American Patient Rights Association. (1992). AHA Patient's Bill of Rights.

Patients Bill of Rights; U.S. Department of Health & Human Services (2023)