



Patient Responsibilities at the Clinical Center

In the spirit of working together toward our common goal, our patients (and their parents, guardians, or surrogates) have certain responsibilities as participants in medical research and as patients at the Clinical Center.

1. The patient (or his/her parents, guardian, or surrogate) has the responsibility to provide, to the best of his/her knowledge, complete information about his/her current medical condition and past medical history, including current illness, prior hospitalizations, current medications, allergies, and all other health-related matters.
2. The patient (or his/her parents, guardian, or surrogate) has the responsibility to discuss his/her protocol (study or treatment plan) with the medical/nursing staff, before indicating agreement by signing a consent to take part in it.
3. The patient (or his/her parents, guardian, or surrogate) has the responsibility to comply with his/her protocol, to cooperate with hospital staff, to ask questions if directions or procedures are not clear, and to participate in his/her health care decisions. Any patient may withdraw from the study for any reason, but it is desirable to discuss his/her concerns with the attending physician before taking that action. Parents of pediatric patients have the responsibility to indicate if and how they want to be involved in their child's plan of care.
4. The patient has the responsibility to refrain from taking any medications, drugs, or alcoholic beverages while participating in the protocol, except those that have been approved by an appropriate NIH physician. Smoking is prohibited in the Clinical Center.
5. The adult patient has the responsibility to inform the medical staff about his/her wishes regarding treatment plans. The patient may provide for a duly authorized family member or spokesperson to make medical decisions on his/her behalf in the event he/she becomes unable to communicate.
6. The outpatient (or his/her parents, guardian, or surrogate) has the responsibility to report on time for scheduled procedures and to keep all clinic appointments. If unable to do so for any reason, the outpatient (or his/her parents, guardian, or surrogate) has the responsibility to notify the protocol physician, and to cancel and reschedule the appointment.
7. The patient (or his/her parents, guardian, or surrogate) has the responsibility to report promptly to the medical or nursing staff any unexpected problems or changes in his/her medical condition.

8. The patient (or his/her parents, guardian, or surrogate) has the responsibility to inform the appropriate staff or the Patient Representative of any concerns or problems with the care and treatment that he/she feels are not being adequately addressed.
9. The patient (or his/her parents, guardian, or surrogate) has the responsibility to respect the property of the U.S. Government, fellow patients, and others; to follow NIH rules and regulations affecting patient care and treatment; and to respect the rights of other patients and hospital staff. This includes the responsibility of respecting the privacy of other patients and treating information concerning them as confidential.
10. The patient (or his/her parents, guardian, or surrogate) has the responsibility to provide his/her own transportation to and from the Clinical Center. The outpatient also has the responsibility to pay for all living expenses—except where all or part of these expenses are specifically covered by the protocol and/or authorized by the responsible NIH physician. The patient has the responsibility to advise accompanying escorts or others who travel to and remain in the Bethesda area that they must pay for their own travel and living expenses, except when designated by NIH as a guardian for a patient whose expenses are covered.
11. The patient (or his/her parents, guardian, or surrogate) has the responsibility for paying all medical or laboratory expenses incurred outside the Clinical Center, except when the patient has been given prior written authorization on the appropriate NIH form to have such expenses billed to NIH.
12. The patient (or his/her parents, guardian, or surrogate) has the responsibility to provide complete information, so that contacts and communications to schedule visits and monitor health status can be maintained. This information should include

the following: (1) the patient's current address and phone number; (2) the names, addresses, and phone numbers of next of kin or persons to be notified in the event of an emergency; and (3) the names, addresses, and phone numbers of physicians responsible for the patient's ongoing care, including the patient's family physician and the physician(s) who referred the patient to NIH.

13. The patient (or his/her parents, guardian, or surrogate) has the responsibility to obtain medical care and medications from his/her own health care provider for all conditions unrelated to the protocol in which he/she is participating, except while being treated as an inpatient at the Clinical Center.

14. The patient (or his/her parents, guardian, or surrogate) has the responsibility to return to the care of his/her own health care provider when participation in the protocol is completed or stopped and the patient's medical condition permits.



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This information is prepared specifically for patients participating in clinical research at the Clinical Center at the National Institutes of Health and is not necessarily applicable to individuals who are patients elsewhere. If you have questions about the information presented here, talk to a member of your healthcare team.

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