



Turning 18 at the NIH Clinical Center:

What it means for your health records and your family

At the NIH Clinical Center, when you turn 18, you become a legal adult in most U.S. states and in your health-care access. This means you now have the right to control your health information and who sees it. This guide helps you and your parent(s)/guardian(s) understand what changes, and what stays the same. Your care team will guide you through these steps.

Key Terms to Know

- Assent** - When a child or teen under 18 agrees to their care or research participation along with a parent's consent.
- Consent** - When an adult (18 or older) gives permission for their own care, treatment, or participation in research.
- Authorization** - Written permission allowing someone else (parent or doctor) to see or receive your health information.
- Confidential Medical Information** - Any data in your record that identifies you (name, date of birth, test results, etc.).
- Privacy Act** - Federal law that protects your personal information that the federal government collects and keeps.
- Proxy** - A person you formally choose to make medical decisions for you if you cannot.

You may also hear terms like *Release of Information (ROI)* or *Power of Attorney (POA)*. These are legal forms that let you give someone permission to see your info or help make choices for you.

What Changes When You Turn 18*

- Under the Privacy Act, once you are 18, you hold all rights to your own confidential medical information.
- You will be asked to sign your own admission and information-privacy consent forms before continuing care or research participation. Your care team will review the research study consent form with you so you can decide whether to continue to participate. If at any time you wish to no longer participate in the research study, you may do so.
- Parents or guardians no longer automatically have access to your records or appointments.
- You now make your own medical decisions and give your own consent for treatment and research.
- You control who can see your medical records or talk to your care team.
- You can still choose to involve your parents or caregivers — it's your decision.

What this Means for Parents and Guardians

- Before 18: Parents/guardians could access your records and make health decisions together with your care team.
- After 18: Access and communication require your permission.
- Parents/guardians can still:
 - Attend visits if you invite them.
 - Help manage appointments and forms (if you authorize them).
 - Continue emotional and logistical support.

If you wish to continue to share your records with your parents/guardians, ask about the [Release of Information \(ROI\) or Authorization Form](#) (also available [in Spanish](#)).

Plan ahead: Start this conversation with your parent(s)/guardian(s) before your 18th birthday. The Health Information Management and Patient Representative staff can help you understand your options.

**There are situations in which these general rules may not apply. Please speak with your care team if you have questions.*

How to Share, or Not Share, Access to your Confidential Medical Information

You decide whether to:

- Authorize a parent/guardian to view your record (complete a [Release of Information form](#)).
- Give a parent/guardian access to your FollowMyHealth patient portal account so they can help manage your care.
- Keep your records private and manage them independently.
- Change or revoke access at any time.

Both of these forms are also available from the NIH Clinical Center Health Information Management Division Office, <https://www.cc.nih.gov/dcric/medical-record-request>

Frequently Asked Questions

Q: Can my parents follow my NIH visits using the patient portal?

A: No. Parent/guardian access ends automatically at age 18.

Q: Can my parents still get my lab results after I turn 18?

A: Yes. You may authorize a parent/guardian to access your health records, including lab results.

Q: Can I share access and change my mind later?

A: Yes. You can revoke authorization at any time.

Q: What if I have a chronic condition and want my parent to stay involved?

A: You can complete an authorization or proxy form for FollowMyHealth access so they can continue helping.

Q: What happens in an emergency?

A: If you can't make decisions, your care team will follow policies and laws to identify a representative, but having an advance directive in place helps ensure your wishes are clear. Some exceptions may apply depending on your medical situation or study requirements. Your care team will explain these if they apply to you.

What To Do Next

- 1) **At age 17 (or before):** Talk with your care team and parent/guardian about your preferences and the possibility of visiting the adult clinic/inpatient unit.
- 2) **Before your 18th birthday:** Request the Release of Information (ROI) form if you want shared access.
- 3) **After turning 18:** Confirm your preferences by completing the ROI form; keep a copy for your files.
- 4) **Anytime:** Update your choices if your situation changes.

**There are situations in which these general rules may not apply. Please speak with your care team if you have questions.*

NIH Clinical Center Resources

[NIH Clinical Center Patient Handbook](#)

Patient Services:

<https://www.cc.nih.gov/patient-services>

Children at the NIH Clinical Center:

Information is prepared specifically for pediatric patients taking part in clinical research at the NIH Clinical Center.

Health Information Management Division:

- Phone: 1-855-644-6445, Monday through Friday (except federal holidays) 7:00 am to 5:00 pm EST.
- Location: Building 10, Room B1L400
- [Release of Information Forms](#)
- [FollowMyHealth Patient Portal](#)

How to Request a Copy of Your Medical Records:

<https://www.cc.nih.gov/dcric/medical-record-request>

Patient Representative: Serves as a link between the patient and the hospital.

- Phone: 301-496-2626
- Email: ccptrep@mail.nih.gov

Patient Services: Resources for Clinical Center Patients

Social Work Department: Assists patients and families with personal and social problems related to illness and hospitalization.

This guide is for general informational purposes and does not replace professional legal or medical advice. For questions, contact the NIH Clinical Center Patient Representative Office at 301-496-2626. © NIH Clinical Center, 2025. All rights reserved.