GEM PATIENT EDUCATION CENTER

Your Rights as a Patient

Version 1.2 · Reviewed 13 September 2026

Be informed. Ask questions. Understand your choices. Keep your records. Speak up for the care you need.

This U.S.-oriented guide combines patient rights with practical advice and GEM care preferences. Legal protections vary by setting and jurisdiction; a good-care recommendation is not automatically a separate legal entitlement. Ask questions and take part in decisions about your care.

1. You have the right to be heard

Your symptoms, concerns, priorities and goals should be taken seriously. You should have the opportunity to participate in decisions about your care and to ask questions until you understand the proposed plan. Severe menstrual or pelvic symptoms should not be dismissed simply because endometriosis can be difficult to diagnose.

2. You have the right to understandable information

You should receive information about your condition, reasonable treatment choices, expected benefits, important risks and alternatives in language you can understand. Ask for clarification, an interpreter or written information when needed. **Understanding your choices is part of informed decision-making.**

3. Informed consent before surgery

Before an operation, you should understand why surgery is recommended, what is planned, important risks and alternatives, and what additional procedures might become necessary if unexpected disease is found. Consent should be obtained **before** the operation, while you are able to make an informed decision.

4. Know who will perform your surgery

Ask who will be the primary surgeon and who else may participate. If deep or multi-organ endometriosis is suspected, ask whether the team has appropriate experience and whether bowel, urologic or other specialists will be available if needed. You may also ask about trainees and their role in your care.

5. You can ask about experience and qualifications

It is reasonable to ask how much endometriosis surgery your surgeon performs, whether they regularly treat ovarian endometrioma and deep disease, and what advanced training they have. MIGS training can be valuable, but it does not automatically establish expertise in every form of complex endometriosis.

6. You can seek a second opinion

If you are uncertain about the diagnosis, proposed treatment, fertility consequences or extent of surgery, you can ask another qualified clinician to review your case. A second opinion can be particularly valuable before major surgery, repeat surgery, ovarian surgery or treatment involving the bowel, bladder, ureter or other organs.

7. Your medical record belongs in your care

HIPAA generally gives access to your health information in a covered entity's designated record set, with limited exceptions. You may request an amendment if information is inaccurate or incomplete. A request is not a guarantee of a change; if denied, you may submit a statement of disagreement.

8. Ask for your operative report and pathology

After endometriosis surgery, request copies of the operative report, pathology report and relevant imaging. These records can be extremely important if symptoms persist, fertility treatment is needed or another operation is considered. Keep them together in your personal health record.

9. Ask about photographs and operative video

GEM favors photographs and complete unedited operative video when feasible, consented and privacy-compliant. Recording is not universally required. Ask what is retained and how to request it. If a recording is in a HIPAA designated record set, access is governed by HIPAA and its exceptions, not simply by preference.

10. You can ask questions before saying yes

Before consenting, ask: **What exactly do you expect to find? What will you treat? What might you leave untreated, and why? Could my ovary, fertility, bowel, bladder or ureter be affected? What happens if disease is more extensive than expected? Who will be available to help?** A consent form should support a conversation – not replace one.

11. Privacy and dignity matter

Privacy and dignity matter. Medicare/Medicaid-participating hospitals must protect patient rights. CMS's 2024 consent clarification addresses sensitive examinations by trainees, especially examinations outside the planned medically necessary procedure. Ask who will participate and what is specifically authorized.

12. You can raise concerns or make a complaint

If you believe your rights, privacy or quality of care have not been respected, start with the clinician, hospital patient-relations office or formal grievance process. Depending on the issue, state agencies, licensing boards, HHS civil-rights/privacy processes, Medicare or other federal programs may also provide avenues for complaints or appeals. Keep copies of relevant records and correspondence.

GEM PATIENT-RIGHTS MESSAGE

YOUR BODY. YOUR INFORMATION. YOUR DECISION.

Ask questions. Know who is treating you. Understand before you consent. Keep your records. Seek a second opinion when you need one.

Evidence & references

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Rights versus recommendations

The guide is U.S.-oriented. 42 CFR 482.13 applies to participating hospitals; HIPAA access applies to covered entities and designated record sets, with exceptions. Rights to refuse/request treatment do not entitle a person to medically inappropriate treatment.

Consent and records

CMS's 2024 memorandum addresses sensitive examinations and training in hospital consent practice. Asking for video creation is distinct from requesting access to a retained record. Amendment requests can be denied with a right to submit disagreement.

Full references

- **[L1]** U.S. Department of Health and Human Services. Your Medical Records. Reviewed 30 May 2025. Freely available
- **[L2]** 42 CFR 482.13. Condition of participation: Patient's rights. Current eCFR text accessed 13 September 2026. Freely available
- **[L3]** Centers for Medicare & Medicaid Services. QSO-24-10-Hospitals: Revisions and clarifications to hospital interpretive guidelines for informed consent. 1 April 2024. Freely available
- **[L4]** 45 CFR 164.524. Access of individuals to protected health information. Current eCFR text accessed 13 September 2026. Freely available

No listed institution endorses GEM.

Medical information

Do not delay care; seek emergency help for a suspected emergency.

This material is for educational purposes only and does not constitute medical advice or create a clinician-patient relationship with GEM.