

appointments and testing

appointments and annual visit

routine visits

You will have routine (regular, ongoing) visits with your IBD provider at least twice a year. You can see a dietitian, psychologist, or other member of your care team at these visits too.

annual visit

Once a year, you will meet with a nurse practitioner (NP) for your annual visit. This is a special office visit to check in on how you are doing physically and mentally. The goal is to improve your health and the quality of care we provide.

The annual visit lasts about 45 minutes. During the visit, you will meet with several members of your care team. These could include:

- Nurse
- Nurse practitioner
- Dietitian
- Social worker
- Physician
- Office coordinator
- Research coordinator

Major areas discussed at the annual visit are:

1. Health maintenance: immunizations, flu shots, bone health, eye health
2. Medications and adherence
3. Self-management
4. Social needs and a school plan (also called 504 education plan) review
5. Emotional needs, including anxiety and depression screening
6. Transition to adult GI care

transitioning from pediatric to adult care

Over time, you will gradually start to manage your care on your own. Learning all about your disease and health care needs is important when transitioning to an adult provider. Here are some key areas you should be able to manage, and a checklist to help you track your progress.

Know:

- Your disease
- Your medicines, including: Name, purpose, dosage, potential side effects and interactions
- Your tests and what the results mean for your ongoing care

Develop independence and assertiveness:

- Take personal responsibility for knowing your medication schedule and adhering to it
- Take responsibility for making your own appointments with the doctor
- Self-report your history to the physician rather than relying on parents and caregivers
- Plan for the future, including: How to manage your disease at school, the types of work you might pursue and all aspects of your health insurance

Health and lifestyle:

- Know the effects of drugs, alcohol and smoking on your disease
- Know the consequences of not following your medication regimen
- Understand the impact of your condition on sexual function and fertility

Use this checklist to help track your progress in managing your disease.

age**	patient knowledge and responsibilities
12-14	<p>Early adolescence</p> <p><i>New knowledge and responsibilities</i></p> <ul style="list-style-type: none"><input type="checkbox"/> I can describe my GI condition<input type="checkbox"/> I can name my medications, the amount and times I take them<input type="checkbox"/> I can describe the common side effects of my medications<input type="checkbox"/> I know my doctors' and nurses' names and roles<input type="checkbox"/> I can use and read a thermometer<input type="checkbox"/> I can answer at least 1 question during my health care visit<input type="checkbox"/> I can manage my regular medical tasks at school<input type="checkbox"/> I can call my doctor's office to make or change an appointment<input type="checkbox"/> I can describe how my GI condition affects me on a daily basis

age**	patient knowledge and responsibilities
14-17	<p>Mid-adolescence</p> <p><i>Building knowledge and practicing independence</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> I know the names and purposes of the tests that are done <input type="checkbox"/> I know what can trigger a flare of my disease <input type="checkbox"/> I know my medical history <input type="checkbox"/> I know if I need to transition to an adult gastroenterologist <input type="checkbox"/> I reorder my medications and call my doctor for refills <input type="checkbox"/> I answer many questions during a health care visit <input type="checkbox"/> I spend most of my time alone with the doctor during visit <input type="checkbox"/> I understand the risk of medical non-adherence <input type="checkbox"/> I understand the impact of drugs and alcohol on my condition <input type="checkbox"/> I understand the impact of my GI condition on my sexuality
17+	<p>late adolescence</p> <p><i>Taking charge</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> I can describe what medications I should not take because they might interact with the medications I am taking for my health condition <input type="checkbox"/> I am alone with the doctor or choose who is with me during a health care visit <input type="checkbox"/> I can tell someone what new legal rights and responsibilities I gained when I turned 18 <input type="checkbox"/> I manage all my medical tasks outside the home (school, work) <input type="checkbox"/> I know how to get more information about IBD <input type="checkbox"/> I can book my own appointments, refill prescriptions and contact my medical team <input type="checkbox"/> I can tell someone how long I can be covered under my parents' health insurance plan and what I need to do to maintain coverage for the next 2 years. <input type="checkbox"/> I carry insurance information (card) with me in my wallet/purse/backpack.

*This checklist and the key areas to help manage were pulled from gikids.org. Search "Transitioning with IBD."

**These ages are general guidelines. Everyone is different, so some adolescents may move through the process at younger or older ages.

immunizations /flu shots

It is important to talk to your GI doctor about any immunization questions. In general, here are our recommendations for immunizations and vaccinations:

recommended 	not recommended 
<ul style="list-style-type: none"> • All standard childhood vaccines • HPV • Meningococcal • Annual flu vaccine for you and your family members 	<ul style="list-style-type: none"> • MMR • Chicken pox • Nasal flu mist • Any live virus vaccines

diagnostic testing and labs

Diagnostic testing is important to diagnosing IBD so we can see what parts of your body are affected and how we can treat you. We also test to see if you are having a flare, and to watch for side effects of any medicines you're taking. You may get your results on MyKidsChart. Your GI nurses may also call with results and your provider's recommendations.

questions to ask before any test/lab:

- What is the purpose of the test? What will happen if we get a positive result?
- How should I prepare for this test? Can I eat and drink beforehand?
- How long will the test take?
- How and when will I learn the results?
- Will I have to do this test or procedure more than once? How often?

Here are some examples of tests/labs you may have:

test name	body part it looks at	what happens during the test	goal of the test
Upper endoscopy (EGD)	Esophagus, stomach, first part of the small intestine	Use flexible tube called a scope to look in the body. The tube has a camera and light on the end.	<ul style="list-style-type: none"> - Looks for redness, swelling, bleeding, ulcers or infections. - Take small samples called biopsies to look at under a microscope.
Lower endoscopy (Colonoscopy)	Entire colon (large intestine)	Use flexible tube called a scope to look in the body. The tube has a camera and light on the end.	<ul style="list-style-type: none"> - Looks for redness, swelling, bleeding, ulcers or infections. - Take small samples called biopsies to look at under a microscope.

test name	body part it looks at	what happens during the test	goal of the test
Blood work/ labs	<ul style="list-style-type: none"> • Complete blood cell count (CBC) • Liver enzymes (AST and ALT) • Ethrocyte sedimentation rate (ESR) and/ or C-reactive protein (CRP) • CMP (comprehensive metabolic panel) 	Take a small amount of blood	<ul style="list-style-type: none"> • CBC: Evaluate for anemia (low red blood cell count), signs of infection, or side effects of medicines • AST/ALT: Evaluate for side effects of medicine and complications of IBD • ESR/CRP: Evaluate for inflammation • CMP: Measures your sugar (glucose) level, electrolyte and fluid balance, kidney function, and liver function
Specialty labs	<ul style="list-style-type: none"> • Medication levels • Vitamin levels • Tuberculosis test 	Take a small amount of blood	<ul style="list-style-type: none"> • Medication levels: Evaluate level of medication, side effects, antibody level • Vitamin levels: Evaluate nutrition • Tuberculosis test: Needed for ongoing monitoring on certain medications
Stool studies	Stool (poop)	Examine your poop when you are having symptoms of a flare	Check for blood, inflammation or certain infections
Radiology studies	Any part of your digestive tract	<ul style="list-style-type: none"> • MRI/MRE: Uses a large magnet and radio waves to create detailed pictures of organs and tissues • CT scan: Combines X-ray images taken around different angles of your body to give more details than X-rays do 	Look for inflammation and check for complications
Capsule endoscopy	Entire GI tract with focus on small bowel.	A wireless capsule-encased micro-camera is swallowed or placed endoscopically if the patient cannot swallow pills. The camera travels through the digestive tract and takes thousands of pictures that are transmitted to a recorder that you wear on a belt around the waist.	Looks for redness, swelling, bleeding or ulcers. The capsule is passed in a bowel movement.