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*Contents of this binder reviewed and updated January 2023*
introduction to Dayton Children’s Hospital

Thank you for choosing Dayton Children’s Hospital for your IBD care! We look forward to taking care of you.

This binder will help you understand what IBD is, how to manage IBD, and give you resources for support.

If you want to access this information online or want to print more copies of the tracking sheets, please visit our online IBD resource center at childrensdayton.org/IBDresources.

Throughout the binder you’ll notice that certain terms are bolded. These are frequently used words in the book, and throughout your IBD care at Dayton Children’s.

For simplicity, we will use “you” to refer to the patient throughout this binder. Using one reference term, rather than “you/your child” throughout will make the document easier to read. However, we know that our patients will need their parents’ help and support in managing IBD. This binder is a resource for them too. We encourage them to read through this binder and be actively involved in your care.

While this binder should answer many of your questions, you can always ask anyone on your IBD team. We are all here to help you.
when to call the doctor

routine calls to the office:

• Lab and X-ray results (may also be in MyKidsChart)
• Prescription refills
• Medical forms or excused absence note for school and work

don’t forget about MyKidsChart!
MyKidsChart is the best way to communicate with us for routine questions or requests. We can sign you up while you’re here, so be sure to ask if you’re not signed up yet! You can also sign up at childrensdayton.org/mykidschart.

urgent calls to the office:

• New rash
• Swollen joints
• Any signs of a flare or change in symptoms (like worsening pain or diarrhea)
• Ongoing temperature greater than 100.4 degrees
• New appearance of blood in stool
• Feeling extra tired
• Mental health changes (coping issues, anxiety, depression, etc.)
• Weight loss of more than five pounds in a few days
• Exposure to someone with tuberculosis or chicken pox

go to the emergency room if you have:

• Sudden or serious change in your condition
• Sudden high fever
• Severe abdominal (belly) pain that lasts for more than an hour
• Persistent vomiting

contact information:

• During normal business hours: 937-641-3090
• For emergency calls after hours or on weekends: 937-641-3000 and ask for the GI doctor on-call
when to call your pediatrician:

Your pediatrician is still your primary caregiver. Call them for any care unrelated to IBD symptoms. Here are some examples:

- Minor illnesses like a cold, ear infection or virus
- Routine care like immunizations, sports physicals, or flu shots

your care team

Our team is made up of experts who want to help you feel your best in every way. See team insert or a list of your specific care team members below:

**IBD doctor/gastroenterologist:**
Name: 
Phone number: 

**nurse:**
Name: 
Phone number: 

**nurse:**
Name: 
Phone number: 

**nurse:**
Name: 
Phone number: 

**dietitian:** Helps you make healthy choices about what you eat and drink
Name: 
Phone number: 

**social worker:** Helps you find resources to help with school, finances, transportation to appointments, etc.
Name: 
Phone number: 

**psychologist:** Helps you learn to handle the ups and downs of living with IBD.
Name: 
Phone number: 

**surgeon (if needed):** Not every child with IBD will need surgery, but if you do, we’ll add an expert to your team.
Name: 
Phone number: 
**your primary care physician:** Helps you with medical concerns that aren’t related to IBD.

Name: 

Phone number:

**my health information**

MyKidsChart login information:

Username: __________________________

Password hint: _______________________

**navigating Dayton Children’s**
**my condition**

This information is important to help you track and manage your condition, and to prepare you to communicate this to new members of your care team. Eventually, it will also help you when you transition your care to an adult provider.

**Location:**

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<tr>
<th>Disease phenotype/severity (its nature):</th>
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Where my IBD affects me (mark on the picture below):

my immunization history

You can track the immunizations you have received here, or use MyKidsChart.

<table>
<thead>
<tr>
<th>immunization/vaccination name</th>
<th>date given</th>
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family history of autoimmune diseases

Please write down family members that have autoimmune diseases, like IBD, rheumatoid arthritis, multiple sclerosis, type 1 diabetes, lupus, psoriasis, or celiac disease.

<table>
<thead>
<tr>
<th>name</th>
<th>relationship to you</th>
<th>autoimmune disease</th>
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<tbody>
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</table>
medication history

medication 1: ________________________________________________________________
Dosage: __________________________________________________________________
Insurance pre-authorization/approval process: ________________________________
Side effects: __________________________________________________________________

Notes: ____________________________________________________________________

medication 2: ________________________________________________________________
Dosage: __________________________________________________________________
Insurance pre-authorization/approval process: ________________________________
Side effects: __________________________________________________________________

Notes: ____________________________________________________________________

medication 3: ________________________________________________________________
Dosage: __________________________________________________________________
Insurance pre-authorization/approval process: ________________________________
Side effects: __________________________________________________________________

Notes: ____________________________________________________________________
medication 4: ________________________________________________________________
Dosage:
Insurance pre-authorization/approval process:
Side effects:
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Notes:______________________________________________________________________
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medication 5: ________________________________________________________________
Dosage:
Insurance pre-authorization/approval process:
Side effects:
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Notes:______________________________________________________________________
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medication 6: ________________________________________________________________
Dosage:
Insurance pre-authorization/approval process:
Side effects:
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Notes:______________________________________________________________________
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medication 7: ________________________________________________________________

Dosage:

Insurance pre-authorization/approval process:

Side effects:

Notes:

medication 8: ________________________________________________________________

Dosage:

Insurance pre-authorization/approval process:

Side effects:

Notes:

medication 9: ________________________________________________________________

Dosage:

Insurance pre-authorization/approval process:

Side effects:

Notes:
<table>
<thead>
<tr>
<th>medication</th>
<th>Date started</th>
<th>Date stopped</th>
<th>Reason discontinued</th>
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medication 5: ________________________________________________________________

Date started: 

Date stopped: 

Reason discontinued: 

Notes: 

medication 6: ________________________________________________________________

Date started: 

Date stopped: 

Reason discontinued: 

Notes: 

medication 7: ________________________________________________________________

Date started: 

Date stopped: 

Reason discontinued: 

Notes: 

medication 8: ________________________________________________________________

Date started: 

Date stopped: 

Reason discontinued: 

Notes:
You should follow your treatment plan until your doctor tells you to stop. If you stop taking your medicines when you begin to feel better, it can cause a flare.

There is no cure for IBD. The goal of treatment is **remission**. Remission means that you feel better and have no signs of **inflammation**. The best way to get to remission is to follow your treatment plan. This is called **adherence**.

Here are some ways to help you follow your treatment plan and stay consistent with your medications/therapies:

- Track the name, dosage, and side effects of medications/therapies
- Set an alarm on your phone for daily medications/therapies
- Use a phone app for tracking medications/therapies
- Use a calendar to track when the next dose is due for your medications/therapies.

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<th>dose instruction</th>
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height/weight log

It is important that you achieve and maintain a healthy growth and weight pattern to heal properly. That can look different for different people at different stages in their disease. Use these pages to track your height and weight at each visit. Plot these numbers on the growth curves on the next pages, too. You can also access this information in MyKidsChart. You can also keep track of your disease activity at the time that the weight and height were taken.

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2 to 20 years: Girls
Stature-for-age and Weight-for-age percentiles

Mother’s Stature Father’s Stature

Date Age Weight Stature BMI*

*To Calculate BMI: Weight (kg) = Stature (cm) + Stature (cm) x 10,000
or Weight (lb) = Stature (in) + Stature (in) x 703

Published May 30, 2000 (modified 11/21/00).
SOURCE: Developed by the National Center for Health Statistics in collaboration with
the National Center for Chronic Disease Prevention and Health Promotion (2000).
http://www.cdc.gov/growthcharts
boys growth chart

2 to 20 years: Boys
Stature-for-age and Weight-for-age percentiles

NAME __________________  RECORD # __________________

Mother’s Stature    Father’s Stature

Date    Age    Weight    Stature    BMI*

*To Calculate BMI: Weight (kg) = Stature (cm) x Stature (cm) x 10,000 or Weight (lb) = Stature (in) x Stature (in) x 703

Published May 30, 2000 (modified 11/21/00).
SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).
http://www.cdc.gov/growthcharts
tracking your stool

You may be asked to describe what your stool (or poop) looks like. Use this chart to better describe the stool to your provider.

<table>
<thead>
<tr>
<th></th>
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<th>rabbit droppings</th>
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<tbody>
<tr>
<td>1</td>
<td></td>
<td>mashed potatoes</td>
</tr>
<tr>
<td>2</td>
<td>bunch of grapes</td>
<td>oatmeal</td>
</tr>
<tr>
<td>3</td>
<td>corn on cob</td>
<td>gravy</td>
</tr>
<tr>
<td>4</td>
<td>sausage</td>
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<thead>
<tr>
<th>date</th>
<th>time</th>
<th>form</th>
<th>was there blood?</th>
<th>urgency</th>
<th>details</th>
</tr>
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<tbody>
<tr>
<td>Jan. 7</td>
<td>6:00pm</td>
<td>6</td>
<td>No</td>
<td>Pretty quickly, I had to get up during dinner</td>
<td>I had a big test and was anxious about that</td>
</tr>
</tbody>
</table>

Example:
<table>
<thead>
<tr>
<th>date</th>
<th>time</th>
<th>form</th>
<th>was there blood?</th>
<th>urgency</th>
<th>details</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>yes/no</td>
<td>How quickly did you have to go?</td>
<td>Did it wake you up if you were sleeping?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Did it interrupt what you were doing at the time?</td>
<td>Do you think a food triggered it?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Did you feel stressed that day?</td>
</tr>
</tbody>
</table>
tracking your pain

To help track the level of pain, you can use one of these pain scales. office visit planner.

pre-verbal / non-verbal
(children ages 2-18)

<table>
<thead>
<tr>
<th>0</th>
<th>2</th>
<th>4</th>
<th>6</th>
<th>8</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 doesn't hurt at all</td>
<td>2 hurts just a little bit</td>
<td>4 hurts a little more</td>
<td>6 hurts even more</td>
<td>8 hurts a whole lot</td>
<td>10 hurts as much as you can imagine</td>
</tr>
</tbody>
</table>

0-10 numeric pain intensity scale
(children ages 8-21 or older)

<table>
<thead>
<tr>
<th>0</th>
<th>2</th>
<th>4</th>
<th>6</th>
<th>8</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>no pain</td>
<td>mild pain</td>
<td>moderate pain</td>
<td>severe pain</td>
<td>very severe</td>
<td>worst possible</td>
</tr>
</tbody>
</table>

date/time | level of pain/discomfort | how long did the pain last? | details/notes

Examples: What were you doing at the time? Did it wake you up if you were sleeping? What did you try to feel better? What was the outcome?
<table>
<thead>
<tr>
<th>date/time</th>
<th>level of pain/discomfort</th>
<th>how long did the pain last?</th>
<th>details/notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Examples: What were you doing at the time? Did it wake you up if you were sleeping? What did you try to feel better? What was the outcome?</td>
</tr>
</tbody>
</table>
# Office Visit Planner

We want to make sure that you get everything you need at your office visits. Bring a copy of this sheet to your next appointment so that your doctor knows what is important to you. This sheet can also be used to update your pediatrician about symptoms.

**Date of appointment:** ________________

- **Changes since your last visit?** (Ex. Symptoms? Concerns? Studies or procedures performed? Medication changes?)
  
  __________________________________________
  __________________________________________
  __________________________________________

- **Questions for your health care provider today?**
  
  __________________________________________
  __________________________________________
  __________________________________________
  __________________________________________

- **Lab/Radiology/Procedure results**
  
  __________________________________________
  __________________________________________
  __________________________________________
  __________________________________________

- **Changes made at today’s visit (including treatment changes and tests/ labs ordered)**
  
  __________________________________________
  __________________________________________
  __________________________________________
  __________________________________________

- **Need any medication refills?**
  
  __________________________________________
  __________________________________________

**Date of appointment:** ________________

- **Changes since your last visit?** (Ex. Symptoms? Concerns? Studies or procedures performed? Medication changes?)
  
  __________________________________________
  __________________________________________
  __________________________________________

- **Questions for your health care provider today?**
  
  __________________________________________
  __________________________________________
  __________________________________________
• Lab/Radiology/Procedure results

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

• Changes made at today’s visit (including treatment changes and tests/ labs ordered)

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

• Need any medication refills?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

preparing for your next appointment

Date of next appointment: ________________________________
To-do’s:
1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________
5. ________________________________

Date of next appointment: ________________________________
To-do’s:
1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________
5. ________________________________

Date of next appointment: ________________________________
To-do’s:
1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________
5. ________________________________
preparing for your next appointment (cont.)

Date of next appointment: _______________________________
To-do's:
1. ____________________________________________________
2. ____________________________________________________
3. ____________________________________________________
4. ____________________________________________________
5. ____________________________________________________

Date of next appointment: _______________________________
To-do's:
1. ____________________________________________________
2. ____________________________________________________
3. ____________________________________________________
4. ____________________________________________________
5. ____________________________________________________

Date of next appointment: _______________________________
To-do's:
1. ____________________________________________________
2. ____________________________________________________
3. ____________________________________________________
4. ____________________________________________________
5. ____________________________________________________

Date of next appointment: _______________________________
To-do's:
1. ____________________________________________________
2. ____________________________________________________
3. ____________________________________________________
4. ____________________________________________________
5. ____________________________________________________
### Schedule for Infusions/Injections

<table>
<thead>
<tr>
<th>January</th>
<th>February</th>
<th>March</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>8 9 10 11 12 13 14</td>
<td>8 9 10 11 12 13 14</td>
<td>8 9 10 11 12 13 14</td>
</tr>
<tr>
<td>15 16 17 18 19 20 21</td>
<td>15 16 17 18 19 20 21</td>
<td>15 16 17 18 19 20 21</td>
</tr>
<tr>
<td>30 31</td>
<td>30 31</td>
<td>30 31</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>April</th>
<th>May</th>
<th>June</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>8 9 10 11 12 13 14</td>
<td>8 9 10 11 12 13 14</td>
<td>8 9 10 11 12 13 14</td>
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<tr>
<td>15 16 17 18 19 20 21</td>
<td>15 16 17 18 19 20 21</td>
<td>15 16 17 18 19 20 21</td>
</tr>
<tr>
<td>30</td>
<td>30</td>
<td>30</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>July</th>
<th>August</th>
<th>September</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
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<td>8 9 10 11 12 13 14</td>
<td>8 9 10 11 12 13 14</td>
</tr>
<tr>
<td>15 16 17 18 19 20 21</td>
<td>15 16 17 18 19 20 21</td>
<td>15 16 17 18 19 20 21</td>
</tr>
<tr>
<td>30 31</td>
<td>30 31</td>
<td>30</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>October</th>
<th>November</th>
<th>December</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>8 9 10 11 12 13 14</td>
<td>8 9 10 11 12 13 14</td>
<td>8 9 10 11 12 13 14</td>
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<tr>
<td>15 16 17 18 19 20 21</td>
<td>15 16 17 18 19 20 21</td>
<td>15 16 17 18 19 20 21</td>
</tr>
<tr>
<td>30 31</td>
<td>30 31</td>
<td>30 31</td>
</tr>
</tbody>
</table>
what is IBD?

Inflammatory bowel disease (IBD) is an autoimmune disease. This means that your immune system mistakes part of your body as foreign. IBD is a chronic condition that causes parts of the intestine (bowel) to get red and swollen. This is called inflammation. Chronic means that you will have IBD your whole life. But, your symptoms may come and go. While IBD is chronic, it is treatable. You can have a normal, happy productive life!

symptoms of IBD

• Diarrhea
• Blood in the toilet, on toilet paper or in the stool (poop)
• Weight loss
• Abdominal pain
• Fever
• Low energy
• Problems around the anus (see image to the right):
  • Skin tags: A small, soft, flesh-colored benign growth of skin, often on a stalk
  • Fissure: A split or tear in the tissue that lines the anus
  • Fistula: An abnormal connection or passageway that connects two organs or vessels that do not usually connect (see picture on page 32)

IBD can also cause symptoms in other parts of your body. These are called extraintestinal symptoms. These happen when the disease is not well controlled or when a complication develops.

• Rashes
• Eye problems
• Joint pain
• Liver problems
• Kidney stones
• Poor growth
• Puberty may happen later than normal
potential complications

- Stricture
- Abscess
- Fistula
- Perforation

types of IBD

The two classified types of IBD are Crohn’s disease and ulcerative colitis. Overall, around 1.6 million Americans have IBD. Around 100,000 of those are children and teens.

Crohn’s disease:

Crohn’s disease is a chronic (never goes away) disease that causes redness, sores and swelling or inflammation in the lining of your digestive tract. The inflammation often affects the entire thickness of the bowel wall. Crohn’s disease can affect any part of the gastrointestinal tract from the mouth to the anus. In Crohn’s disease, the inflammation of the intestine can “skip” leaving normal areas in between patches of the diseased intestine.

Ulcerative colitis:

Ulcerative colitis (or UC) is also a chronic inflammatory bowel disease that mostly affects the large intestine (or colon). Ulcerative colitis causes sores called ulcers that affect the surface of the colon. Unlike Crohn’s disease, the distribution of the inflammation is more continuous and uniform versus having “skipped” areas. The ulcers produce mucus or pus.

IBD unclassified:

IBD unclassified (also known as indeterminate colitis) is when it is not clear if inflammation is due to Crohn’s or ulcerative colitis. About 15 percent of patients diagnosed with IBD have unclassified colitis. Over time, your GI provider may be able to determine what type of IBD you have (Crohn’s or ulcerative colitis).

what causes IBD?

The exact cause is not clear. Researchers think that it may be a combination of genetics and/or environmental triggers that disrupt the immune system. This altering of the immune system can cause IBD. IBD can run in families.

is IBD different than IBS?

Yes. Irritable bowel syndrome (IBS) is also a problem related to the intestines and shares many symptoms of IBD, like abdominal pain and diarrhea. However, in IBS the muscles of the intestines either move too quickly or too slowly. IBS does not cause inflammation.

The treatments for these two conditions are also very different. IBS treatments include diet changes and stress management. While these things may help IBD symptoms, IBD treatment can also include medications, nutrition therapy, hospitalization or surgery.
Since IBD is a chronic disease, there can be times after remission when you have symptoms again. These times when symptoms reappear are called flares, or flare-ups. Report your symptoms early so that your doctor can provide the best advice for you. Avoiding a flare is better than treating one. Taking your medications as recommended can help prevent a flare.

Different factors can increase the risk of flares or symptoms.

- Smoking is an unhealthy habit that can also increase the risk of having a flare.
- Drinking alcohol can:
  - Affect the GI tract and the liver
  - Increase the risk of developing nausea, vomiting, GI bleeding and diarrhea
  - Worsen IBD effects on the liver and lead to liver failure
  - Interact poorly with some IBD medications (like Methotrexate)
- Antibiotics can increase the risk of developing diarrhea, C difficile colitis and flares.
- Caffeine can cause diarrhea, which can be confused with symptoms of a true flare.
- Herbal teas or supplements may have hidden ingredients that could interact with your IBD medicines. Talk to your GI provider before you use these.
- Nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and naproxen (Advil(R), Aleve(R)) can trigger a flare.

Symptoms of a flare may include:

- Abdominal pain
- Cramping
- Blood in bowel movements
- Diarrhea/increased bowel movements
- Nausea/vomiting
- Fever, with no source of infection
- Joint pain
- Fatigue (extreme tiredness)
- Loss of appetite
- Weight loss
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.

<table>
<thead>
<tr>
<th>age**</th>
<th>patient knowledge and responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>12-14</td>
<td>Early adolescence</td>
</tr>
<tr>
<td></td>
<td>New knowledge and responsibilities</td>
</tr>
<tr>
<td></td>
<td>□ I can describe my GI condition</td>
</tr>
<tr>
<td></td>
<td>□ I can name my medications, the amount and times I take them</td>
</tr>
<tr>
<td></td>
<td>□ I can describe the common side effects of my medications</td>
</tr>
<tr>
<td></td>
<td>□ I know my doctors’ and nurses’ names and roles</td>
</tr>
<tr>
<td></td>
<td>□ I can use and read a thermometer</td>
</tr>
<tr>
<td></td>
<td>□ I can answer at least 1 question during my health care visit</td>
</tr>
<tr>
<td></td>
<td>□ I can manage my regular medical tasks at school</td>
</tr>
<tr>
<td></td>
<td>□ I can call my doctor’s office to make or change an appointment</td>
</tr>
<tr>
<td></td>
<td>□ I can describe how my GI condition affects me on a daily basis</td>
</tr>
<tr>
<td>age**</td>
<td>patient knowledge and responsibilities</td>
</tr>
<tr>
<td>-------</td>
<td>----------------------------------------</td>
</tr>
</tbody>
</table>
| 14-17 | **Mid-adolescence**<br>Building knowledge and practicing independence  
- I know the names and purposes of the tests that are done  
- I know what can trigger a flare of my disease  
- I know my medical history  
- I know if I need to transition to an adult gastroenterologist  
- I reorder my medications and call my doctor for refills  
- I answer many questions during a health care visit  
- I spend most of my time alone with the doctor during visit  
- I understand the risk of medical non-adherence  
- I understand the impact of drugs and alcohol on my condition  
- I understand the impact of my GI condition on my sexuality |
| 17+   | **late adolescence**<br>Taking charge  
- I can describe what medications I should not take because they might interact with the medications I am taking for my health condition  
- I am alone with the doctor or choose who is with me during a health care visit  
- I can tell someone what new legal rights and responsibilities I gained when I turned 18  
- I manage all my medical tasks outside the home (school, work)  
- I know how to get more information about IBD  
- I can book my own appointments, refill prescriptions and contact my medical team  
- 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.  
- 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:

<table>
<thead>
<tr>
<th>recommended</th>
<th>not recommended</th>
</tr>
</thead>
<tbody>
<tr>
<td>• All standard childhood vaccines</td>
<td>• MMR</td>
</tr>
<tr>
<td>• HPV</td>
<td>• Chicken pox</td>
</tr>
<tr>
<td>• Meningococcal</td>
<td>• Nasal flu mist</td>
</tr>
<tr>
<td>• Annual flu vaccine for you and your family members</td>
<td>• Any live virus vaccines</td>
</tr>
</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>test name</th>
<th>body part it looks at</th>
<th>what happens during the test</th>
<th>goal of the test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upper endoscopy (EGD)</td>
<td>Esophagus, stomach, first part of the small intestine</td>
<td>Use flexible tube called a scope to look in the body. The tube has a camera and light on the end.</td>
<td>- Looks for redness, swelling, bleeding, ulcers or infections. - Take small samples called biopsies to look at under a microscope.</td>
</tr>
<tr>
<td>Lower endoscopy (Colonoscopy)</td>
<td>Entire colon (large intestine)</td>
<td>Use flexible tube called a scope to look in the body. The tube has a camera and light on the end.</td>
<td>- Looks for redness, swelling, bleeding, ulcers or infections. - Take small samples called biopsies to look at under a microscope.</td>
</tr>
<tr>
<td>test name</td>
<td>body part it looks at</td>
<td>what happens during the test</td>
<td>goal of the test</td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------------------------------------------------</td>
<td>---------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Blood work/labs</td>
<td>• Complete blood cell count (CBC)</td>
<td>Take a small amount of blood</td>
<td>• CBC: Evaluate for anemia (low red blood cell count), signs of infection, or side effects of medicines</td>
</tr>
<tr>
<td></td>
<td>• Liver enzymes (AST and ALT)</td>
<td></td>
<td>• AST/ALT: Evaluate for side effects of medicine and complications of IBD</td>
</tr>
<tr>
<td></td>
<td>• Ethrocyte sedimentation rate (ESR) and/or C-reactive protein (CRP)</td>
<td></td>
<td>• ESR/CRP: Evaluate for inflammation</td>
</tr>
<tr>
<td></td>
<td>• CMP (comprehensive metabolic panel)</td>
<td></td>
<td>• CMP: Measures your sugar (glucose) level, electrolyte and fluid balance, kidney function, and liver function</td>
</tr>
<tr>
<td>Specialty labs</td>
<td>• Medication levels</td>
<td>Take a small amount of blood</td>
<td>• Medication levels: Evaluate level of medication, side effects, antibody level</td>
</tr>
<tr>
<td></td>
<td>• Vitamin levels</td>
<td></td>
<td>• Vitamin levels: Evaluate nutrition</td>
</tr>
<tr>
<td></td>
<td>• Tuberculosis test</td>
<td></td>
<td>• Tuberculosis test: Needed for ongoing monitoring on certain medications</td>
</tr>
<tr>
<td>Stool studies</td>
<td>Stool (poop)</td>
<td>Examine your poop when you are having symptoms of a flare</td>
<td>Check for blood, inflammation or certain infections</td>
</tr>
<tr>
<td>Radiology studies</td>
<td>Any part of your digestive tract</td>
<td>• MRI/MRE: Uses a large magnet and radio waves to create detailed pictures of organs and tissues</td>
<td>Look for inflammation and check for complications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• CT scan: Combines X-ray images taken around different angles of your body to give more details than X-rays do</td>
<td></td>
</tr>
<tr>
<td>Capsule endoscopy</td>
<td>Entire GI tract with focus on small bowel.</td>
<td>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.</td>
<td>Looks for redness, swelling, bleeding or ulcers. The capsule is passed in a bowel movement.</td>
</tr>
</tbody>
</table>
## treatment for IBD

### medications

<table>
<thead>
<tr>
<th>class/type</th>
<th>brand name</th>
<th>what it’s used for</th>
<th>things to consider</th>
</tr>
</thead>
</table>
| Biologics           | • Infliximab (brand name: Remicade)  
• Humira  
• Entyvio  
• Stelara | • Targets a chemical known to cause inflammation  
• Given by IV or injection  
• Used for more moderate or severe disease. | Biologics may have the following possible side effects:  
• Tiredness  
• Headache  
• Risk of infection  
• Development of antibodies |
| Biosimilars         | • Renflexis  
• Inflectra | | |
| Immunomodulators/Immunosuppressants | • 6 MP/azathioprine (Imuran)  
• Methotrexate | Adjust the activity of the immune system | Blood work may be needed before starting to help determine dosage. Immunomodulators may have the following side effects:  
• Pancreatitis (6MP/azathioprine)  
• Vomiting (methotrexate)  
• Decreased white blood cell count  
• Elevated liver enzymes |
| Corticosteroids     | Oral:  
• Deltasone (prednisone)  
• Entocort (budesonide)  
• Uceris (budesonide-MMX)  
Rectal:  
• Hydrocortisone  
• Methylprednisolone  
• Cortenema  
• Proctofoam-HC  
• Uceris  
IV forms:  
• Solumedrol, Solu-Cortef | Help decrease inflammation | Steroids may have the following side effects:  
• Stomach irritation (take with food)  
• High blood pressure  
• Rounding of the face  
• Weight gain  
• Acne  
• Mood swings  
• Increased risk for infection  
• Insomnia (can’t sleep) |

Do not stop taking steroids without talking to your doctor.
biosimilar medicines

Some complex diseases are treated with medicines called biologic medicines or ‘biologics.’ Biologics are made from living cells. Examples of biologics are proteins that bind to specific areas or targets in the body. Usually, biologics are given as an injection (shot) under the skin or an infusion in the vein (IV).

Biosimilar medicines are highly similar to their original biologic and are made from similar living cells. Biosimilars have been used in Europe since the early 2000s, and they have proven comparable with no increased side effects. A few important notes about biosimilar medicines:

1. Many people may be concerned that the brand name biologic medicines works better than the biosimilar medicines. Biosimilars can only be approved by the Food and Drug Administration (FDA) if many tests have been done to show that they work the same and are as safe as the brand name biologic medicines.

2. Biosimilars are given exactly the same way with the same dose and checking the medicine level in the body.

3. Your insurance provider may prefer the biosimilar medicine. This could save you money. There are assistance programs available for patients who have commercial insurance to help keep out-of-pocket costs low.

avoiding NSAIDS

Nonsteroidal anti-inflammatory drugs, or NSAIDS, are used for treating conditions that cause inflammation, pain and fevers. Common examples of these include aspirin, ibuprofen (Motrin®, Advil) and naproxen (Aleve, Naprosyn®). People with IBD should not use NSAIDS because they can trigger a flare-up.
Enteral Nutrition Therapy

Enteral Nutrition Therapy is evidence-based and has been shown to help achieve remission in Crohn’s disease. On this diet, a majority of your intake consists of nutrition shakes with a small amount of regular foods. You can either drink the nutrition shakes, receive them by nasogastric tube (see section on Nutrition Support below), or a combination of the two. This diet has only minor side effects. Benefits include intestinal healing and improved growth. This diet can be used as a short-term or long-term option.

surgery

Each patient is different. Some patients may never need surgery, while others may need it right after diagnosis. This is a decision that you, your parent, and your provider should make together. This is called shared decision making. You and your provider will work closely together to determine if surgery is the best option, or if there are other ways to manage your symptoms. If you and your provider decide that surgery is needed, your surgeon will be a valuable member of your care team. If you have any questions about surgery, please talk to your provider.

nutrition support

It is possible that you may need nutrition support at some point during your journey with IBD. Nutrition support is considered if you are unable meet your calorie and fluid needs through eating and drinking. There are two ways someone might receive nutritional support, either by enteral or parenteral infusion.

Enteral nutrition uses a thin, flexible tube that goes into your body through a nostril and empties into the stomach or small intestine. A nutrition supplement is given and will provide some or all of the nutrients your body needs on a daily basis.

Parenteral nutrition or “TPN” is administered by IV and would be needed when enteral nutrition is not possible. With TPN, the nutrients are delivered directly into the bloodstream rather than the stomach or intestines.

supplements & natural interventions

Children with IBD sometimes take natural supplements or therapies to help with symptoms. Talk to your doctor before adding these to your care plan. Do not stop taking your prescribed medications.

Common natural therapies include:

• Vitamins
• Supplements
• Herbal medicines
• Essential oils
• Acupuncture
• Special diets
• Megavitamins
• Probiotics
• Hypnosis

Discuss any thoughts of these complimentary treatments with your GI doctor.
probiotics

Probiotics are live bacteria that are similar to the bacteria that normally reside in your gut. Some studies show that people with IBD have less “good” bacteria in their bodies. Probiotics can help to restore the balance of bacteria in your gut. Probiotics are found in foods and in supplements, usually capsules or powders. Probiotic containing foods include: kefir, miso, tempeh, kimchi, sauerkraut, and some yogurts and juice beverages. Please consult your care team before starting a probiotic supplement.

general nutrition

overview

In general, a balanced diet is recommended for all children with IBD. Using the MyPlate method can be a great way to ensure that you are getting the nutrients your body needs. Have a meal or snack every few hours and try to incorporate all food groups throughout the day.

Depending on your growth and nutrition status, you may be asked to drink some nutrition shakes by your care team. Nutrition shakes help to boost your intake of calories and protein, and normally include vitamins and minerals as well.

Because IBD can impact absorption, you may need to take a multivitamin or single vitamin supplement such as Vitamin D or folic acid in order to ensure you are meeting your vitamin and mineral needs. Your gastroenterologist and registered dietitian will work together to determine an appropriate plan for you.

It is important to drink plenty of fluids, especially water, in order to stay hydrated. Talk with your team about your specific needs. Remember: Caffeinated beverages do not count toward your fluid goal.

diet to help manage symptoms

You may hear or read about different diets for IBD. In most cases, these are not based on research and may not be best for your child. There is no evidence to suggest that one existing diet helps with symptoms or achieves remission in all children with IBD. If you have questions about any diet for IBD, please contact your registered dietitian.

Specific Carbohydrate diet

The Specific Carbohydrate diet is an exclusion diet with limited research. This diet is not for all disease types. It excludes starches and grains, legumes, processed foods, and most dairy products. More research studies are currently being done on this diet.
eating during a flare

With IBD, you may find that eating certain types of food can cause your symptoms to get worse. These are called trigger foods. Every child is different, so there are no foods everyone should avoid. It may be helpful for you or your child to keep a food symptom journal. Keeping a food symptom journal can help you to track how your diet might relate to the symptoms you are having and identify trigger foods.

<table>
<thead>
<tr>
<th>if you are experiencing a flare, it may be helpful to eat foods that are easier on the stomach such as:</th>
<th>These foods may cause increased cramping, bloating, and diarrhea during a flare. Try to avoid:</th>
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</thead>
<tbody>
<tr>
<td>• Refined or grains that are low in fiber (ex. White bread and pasta)</td>
<td>• Greasy, fried foods</td>
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<tr>
<td>• Soft, bland foods</td>
<td>• Foods high in lactose (ex. Milk and cheese)</td>
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<tr>
<td>• Lower fiber fruits</td>
<td>• Whole grain foods (ex. Wheat bread and brown rice)</td>
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<td>• Lean meats</td>
<td>• Raw vegetables</td>
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<tr>
<td>• Cooked vegetables without skin</td>
<td>• Spicy foods</td>
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<tr>
<td>• Lean meats</td>
<td>• Caffeinated foods or beverages</td>
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exercise

Doing regular physical activity is an important part of staying healthy. Exercising can help improve your mood, relieve stress, reduce depression and anxiety, and strengthen your immune system. It is recommended that children and adolescents age 7-17 years old do one hour or more of moderate to vigorous physical activity daily.

During periods of increased IBD symptoms, you may feel tired or unable to exercise. At these times, it is best to limit exercise and let your body rest. Ask your doctor if there are any restrictions on the type or amount of exercise you can do.
mental health and wellness

coping with IBD

Being diagnosed with IBD may make you feel afraid, sad, nervous or just “different.” These feelings are completely normal. If any of the below behaviors start happening and getting in the way of your life, you may be having trouble coping:

- Difficulty sleeping
- Poor eating habits
- Ongoing sadness, irritability, and/or frequent crying
- Worry that’s very hard to control
- New problems with concentration
- Lack of interest in usual activities and hobbies
- Body image struggles due to changes in your appearance

If you are having trouble, it is so important to know that it is normal to have some difficulty adapting to life with a chronic illness. Learning to cope with IBD often gets easier with time, but it is very reasonable to need some help adjusting. Often parents can be a great source of comfort and help. Other times kids find that talking to close friends is just what they need. Speaking with a psychologist who works with kids dealing with chronic illness and can help you learn specific tools for coping with stress like this might also be helpful. You can also speak with your religious leader, if that feels helpful to you.

Please know that whatever path(s) you choose, you deserve to feel like you can share about your IBD and feel supported. Staying silent about your struggles can cause social isolation and feelings of loneliness. Talking about your condition can help break down barriers and give people an opportunity to help support you!

ImproveCareNow toolkits

These toolkits share real experiences from IBD patients. Sharing stories can help make IBD patients feel supported and not alone. Teens and young adults that have IBD share everything from how their friends reacted to sharing about IBD, how to take care of your mental health, boosting your energy, and dealing with body image issues. Below are links to a couple of the toolkits, but there are many more:

- Talking about IBD: improvecarenow.org/talking_about_IBD
- Body image toolkit: improvecarenow.org/pac_body_image_toolkit
- Accommodations toolkit: improvecarenow.org/new_resource_pac_accommodations_toolkit
the mind and body connection

Although we diagnose IBD based on the physical symptoms in a person's body, there are many other factors that can affect how bad symptoms get and how much they get in the way of your life. The good news is that kids and teens can take control of some of these other factors and make a difference in their experience with IBD.

what is the stress response?

One way the body and the mind are connected is through the body's stress response. The stress response is designed to protect people. When in stressful situations, your body reacts in many ways, such as:

• Making your heart pump faster to move blood quickly to your organs and muscles
• Your short-term memory changes so you can pay attention to danger (which makes it hard to concentrate on things)
• Digestion stops, and your body tries to quickly rid itself of anything left in the stomach so it doesn’t waste energy

When the body is focused on dealing with the stress response, it can’t devote as much effort and resources to maintaining a healthy immune system or healing up after a flare. This is significant for kids and teens with IBD since we really want to clear the way for our body to stay healthy and recover when it gets sidelined by a flare.

imagine this: the stress response at work

Imagine for a moment that you’re a cave-person hanging out by a fire when you notice a saber-tooth tiger walking toward you, licking its lips and looking hungry. Bodies are made to protect us in situations like this. When our eyes catch a glimpse of a hungry saber-tooth tiger, that visual will trigger a host of physical responses (like the ones described above) to help us survive! These physical responses help us take big action quickly, which makes them helpful in saber-tooth tiger-like situations, but are usually not as useful for modern-day stressors.

ways to manage your body’s stress response

It's important to know the kinds of things we have control over that tend to trigger the body's stress response. A lot of times we talk about stress like it's only about how we're thinking and feeling emotionally, but the body makes sense of stress more broadly. A stress response can be triggered as much by worried thoughts about IBD symptoms acting up while you're in class as it can by a lack of healthy habits that the brain expects the body to be performing to keep it healthy and in good shape. So when we think about controlling the stress response in the body, we want to think about healthy habits the body knows it needs in order to function well, as well as management of emotional and social stress. Here are some things kids and teens can do to keep the body’s stress response in check:

1. Sleep:
   a. Aim to keep a consistent sleep schedule, including similar bedtimes and wake times, even on the weekends!
   b. Limit caffeine intake, especially later in the day.
   c. Create a restful environment 20-30 minutes prior to bed time. Darken the room, shut the doors, and cover the windows.
   d. Turn off all devices at least 20-30 minutes before bedtime, including smartphones, tables, computer monitors and televisions.
e. Make sure the bed is reserved for sleeping and sleeping alone and the bedroom isn’t filled with lots of devices and other distractions. This helps the brain start to use your bed and bedroom as a cue for sleep!

2. Nutrition/Hydration:
   a. Eat a well-rounded diet that includes fruits, vegetables, and lean protein.
   b. Avoid processed junk food.
   c. Ask your GI doctor and/or dietitian about the possibility of trigger foods. Trigger foods are generally high in fiber or fat. They may contain lactose, caffeine, alcohol, sugar alcohols or spicy flavors. For some people, getting to know trigger foods and avoiding them can help their bodies function better.

3. Exercise:
   a. Aim for at least 60 minutes or more of heart-pumping activity per day.

4. Social/Emotional Health:
   a. Try to keep a daily routine that includes pleasant activities, especially when you’re going through adjustment to a new diagnosis or having a rough patch.
   b. Talk to someone if you’re starting to feel overwhelmed, like a parent, friend, coach, or therapist.
   c. Make a point of creating space for relaxation in your day, regardless of whether stress is high. Relaxation means different things for different people, so start exploring a variety of activities and get to know what feels relaxing for you.
People with IBD can live happy, healthy lives. A little preparation and planning can help make you more comfortable at school, when you travel, and at work (if relevant). This binder contains a high level overview of handling these situations. We encourage you to go online at the links listed for more information and resources.

section 504 plans for K-12

Children with IBD may miss school for medical appointments, illness, disease flare-ups, and side effects of treatment. A section 504 plan is used to help educate and inform your school of your symptoms and any accommodations you may need. The basics of the letter include an overview of IBD, an introduction to the plan, the students’ symptoms and needs, and emergency contacts.

The Crohn’s & Colitis Foundation recommends that all students with IBD have a 504 plan in place at the beginning of the school year, even if they are feeling well. Your child can be symptom free (in remission) at the beginning of the school year, but may experience active symptoms (flare up) later in the school year. Just because you have a plan in place, does not mean you must use all of the accommodations.

What is a 504 plan?

Section 504 of the Rehabilitation Act of 1973 enables students with disabilities to receive accommodations to ensure academic success and flexibility in their learning environment. It should contain a list of accommodations, or adjustments, which may be required by a child with IBD to ensure that they are treated fairly and have the same access to education as other students. This law typically applies to public schools – but can also apply to private schools, if the school receives federal funding.

A 504 plan is developed by the legal guardian(s), student, and school staff. Many schools have their own version of a 504 plan and it is perfectly appropriate to use the school’s form. However, take care to review it to make sure that it includes the accommodations needed for your child. You can also download an electronic version from the Crohn’s and Colitis Foundation here: crohnscolitisfoundation.org/resources/template-section-504-plan.html.

How do I set up a 504 plan?

1. Your parent/guardian will contact the school to set up a 504 plan meeting. You’ll usually meet with a guidance counselor or administration before the school year begins, to make sure your accommodations are in place.

2. During the meeting, you’ll need to bring a note from your GI team (your MD, NP or social worker) to confirm your IBD diagnosis and request accommodations. You’ll discuss:

   • The accommodations that you’d like to set up

      i. Include anything you think you need for the year, even if you’re in remission. If the school tries to remove something because it’s not currently necessary, emphasize that IBD symptoms change over time and may become active during the school year, so it should remain in the plan.

continued on next page
• How the school can provide support

• What your responsibilities as a student are. (NOTE: Schools are allowed to reject your requests if they are deemed unreasonable).

3. Ensure that all of your teachers are aware of, and understand, the plan. The plan is a shared responsibility.

4. If your 504 plan isn’t providing enough support, your parent/guardian can request an updated plan. Changes can be made to the plan throughout the year at the school’s discretion and the parent’s request. Open communication with you, your parents and the school. (NOTE: Schools may have requirements that make students ineligible for specific accommodations).

5. The plan is only good for one year. So, a plan must be created or updated every year even if you’ve had no changes in your health.

What are some common 504 plan accommodations for IBD patients?

504 accommodations include but aren’t limited to the following:

• Unlimited restroom access
• Stop-the-clock testing
• Access to health center
• Exemption from physical education classes
• Flexible attendance for medical causes (arriving late, leaving early/during class, etc.)
• Options to make up missed class time for medical reasons without penalty
• Full participation in extracurricular activities despite classroom absences
• Tutoring following a period of absence due to complications of IBD

Tip: Your needs are unique! The accommodations that work for another student may not be the best fit for you, so think about the specific difficulties you have when planning accommodations.

Do’s and don’ts of creating a 504 plan

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<th>do’s</th>
<th>don’ts</th>
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<tr>
<td>Make sure you are able to identify your needs, and involve your parents for help</td>
<td>Assume your parent is aware of their accommodations</td>
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<tr>
<td>Include how/where/when/why accommodations will be implemented. Be specific.</td>
<td>Assume your school is implementing the 504 plan</td>
</tr>
<tr>
<td>Create a 504 plan even if you are healthy at the beginning of the year</td>
<td>Assume every teacher, substitute, coach and administrator is aware of the 504 plan</td>
</tr>
<tr>
<td>Make sure the plan is communicated well with the teachers, and check that the current plan is working well</td>
<td>Feel embarrassed creating or having a plan - Know it’s okay to get help when you need it</td>
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</table>
How do I get accommodations if I attend a private school?

Because private schools do not utilize government funding, they are not required to offer 504 plans. However, there are still ways to receive accommodations. The process will likely vary depending on the private school, but generally you will need to:

1. Email the nurse, counselor and/or teachers to let them know of your diagnosis.

2. Speak with your counselor and discuss the accommodations that you may need (ex: frequent access to the bathroom, keeping supplies in the nurse's office). To avoid having an urgent need for an accommodation in an unexpected situation, make sure to ask for any accommodations you may need later in the year.

3. The counselor should then notify your teachers of the accommodations you need.

4. Follow up with your counselor yearly to make sure your accommodations are still intact and updated to your needs.

What if the school doesn’t agree to my proposed 504 plan?

Assuming your requests are reasonable, the school is legally required to grant your 504 plan. Parents/guardians can request a due process hearing if they disagree with the decision made regarding the school district’s decision, and a complaint can be filed with the district’s 504 coordinator. See “Notice of Parents and Student Rights” under the Section 504 of the Rehabilitation Act for more information.

for more information

Visit the Crohn’s and Colitis Foundation website, crohnscolitisfoundation.org for more information and resources on 504 plans.

college

Transitioning from home to college can be stressful. Planning and preparation can help the transition go smoothly. Here are some high level tips:

Choosing a college:

Ask questions of schools you're interested in before you go so you can choose a college where you can thrive. For example:

- Can you get a private bedroom or bathroom?
- Are there pharmacies nearby?
- What kinds of meal plans and dining options does the school have?
- Can I get excused absences when I am sick?

Once you've decided which college you will attend, talk to the organizations that can help it be more comfortable. These can include student housing, residence life, food services, a disability resource center, etc. If possible, try to meet with them ahead of time.
Once you arrive:

- Meet with disability services first so that you have any paperwork your professors might ask for. Section 504 of the Rehabilitation Act of 1973 also protects students in higher education. Unlike high school, you must seek out services and advocate on for yourself. Students must voluntarily disclose that they have IBD, provide documentation, and request support or accommodations you need. Share this with disability services, and with your professors.

- When classes start, talk to your professors about your disease. They can help work with you to meet your needs.

- Meet the doctors and nurses in your health clinic.

- Learn where the bathrooms are near your classes and in your dorm.

- Buy snacks that you can eat if you're not feeling well or if you can't find a lot of options at school.

- Once you feel comfortable, talk to your roommate and friends about IBD.

- Pay attention to how you're feeling, and know when you need rest.

Most of all, enjoy it! College is a great time to learn more about yourself, meet lots of new people and have fun, new experiences. With the right preparation, you can be happy and successful in college.

**for more information:**

Crohn's and Colitis Foundation has a great section on navigating college with IBD. To view those resources, go to crohnscolitisfoundation.org/campus-connection.

**work**

Just like college, being prepared and communicating about IBD can help you feel more comfortable at work. It is always your choice who and when you share about your disease with. Once comfortable, share with your employer any needs that you may have. For example, if your symptoms are worse in the morning, let your boss know that you may be in late for that reason.

Work stress is hard to avoid, so know what you can do to make you feel more relaxed. That could be taking a walk around the block, listening to a calming playlist or taking a quick break to chat with friends.

As always, getting a good night’s sleep, eating well and exercising can all help you take care of yourself and feel your best.

**travel**

Before you leave for any trip, make sure you're prepared to care for any symptoms while you're away. Here are some tips to help you plan ahead of time:

- Bring enough medication to last through your trip.

- Always carry your medication with you on the plane, and keep it in its original container.

- Ask your doctor for a written plan of action in case your condition worsens while you're traveling.

- Know where restrooms are. Find out in advance whether your transportation vehicles have toilets. Request an aisle seat on a plane.
• Keep your doctor’s phone number and your insurance card in your wallet.
• Always travel with your own toilet paper, soothing wipes, ointments and changes of underwear and clothes.
• Know danger signals, and call your doctor if you experience:
  • High fever and shaking chills
  • Profuse bloody diarrhea
  • Severe stomach pain and/or distension (expansion)
  • Dizziness on standing up, or fainting
  • Scanty, concentrated urine

If you’re traveling internationally, there are more things to consider:

• Learn the lingo: Know how to say “toilet” or “bathroom,” “emergency” or “urgent,” and “pharmacy” and “doctor” in the local language. Downloading an app or getting a book that can help you translate is also a good idea.

• Ask your health insurance carrier whether your policy covers foreign travel. Look into international medical insurance too.

• Avoid traveler’s diarrhea by not drinking the water or ice, eating cooked fruits and vegetables or ones that you peel yourself, avoiding uncooked dairy products, and being careful not to swallow the water when swimming or showering.

• Find a doctor. The American Embassy or the International Association for Medical Assistance to Travelers have lists of doctors in other countries.
resources

There are many great organizations that are here to support you. From initial diagnosis, to flares and remission, these resources can help answer a lot of your questions about life with IBD. Of course, your Dayton Children’s IBD care team is always here to help, too.

organizations and support groups

- Dayton Children’s Hospital: childrensdayton.org

- IBD Resource Center: Visit our IBD resource center at childrensdayton.org/IBDresources to access all of the information from this binder online. You can also download and print copies of the tracking sheets.

- Research and quality improvement: Dayton Children’s Hospital is participating in multiple research and quality improvement projects regarding IBD patients. Some areas of research and quality improvement projects include:
  - Combined medications
  - Obesity in IBD
  - Body image
  - Timing between new diagnosis to starting treatment
  - New medication trials
  - Patient-reported-outcome (PRO) studies

- ImproveCareNow (ICN) partnership: By being part of ImproveCareNow (more information below), you can be assured that you are receiving world-class care. A group of clinicians (GI doctors, surgeons, psychologists, and nurse practitioners), social workers, dietitians, researchers, and parent representatives meet several times a month to discuss IBD patients and provide input. ICN focuses on four interventions:
  - Population management
  - Pre-visit planning
  - Care protocols
  - Audit tools

- Parent Advisory Council: Dayton Children’s hosts a parent advisory council. This group shares feedback to affect change on everything from patient family education to overall hospital experience. Made up of parents of newly diagnosed kids to patients who are now in college, this is a great place to have your voice heard. We also have an IBD FACT (Family Action Collaborative Team). The group meets monthly. To join, contact a family partnership coordinator at 937-641-3306.
• **Parent Partners**: Parents are the experts when it comes to their children. Your ideas and experiences are the key to helping us give children the best possible care. Parent partners are volunteers who share their stories, give us advice, and tell us what matters most to families.

Just like our children, parent partner opportunities come in all shapes and sizes. The following opportunities are currently available:

- **Our E-Advisory council** uses a private Facebook page called “Parent Partner Insider.” Caregivers are encouraged to answer polls, provide feedback on hot topics and tell us what is important.

- **Our family action collaborative teams** are made up of parents and staff members working together to improve care in a specific department or around a certain medical condition.

- **Our patient family advisory council and The Center for Community Health and Advocacy** meet monthly to offer input on issues that impact all children and the community.

- **Our parents encouraging parents** mentors have extensive experience with their own child and are trained to provide support through email and/or phone with a parent or caregiver facing a new diagnosis or on-going medical condition.

If you would like more information about how you can become part of our team, please contact our family partnership coordinator, Teresa Prouty, at parentpartners@childrensdayton.org or call 937-641-5904.

- **Crohn’s and Colitis Foundation (CCF):** crohnscolitisfoundation.org
  - The Crohn’s and Colitis Foundation is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn’s disease and ulcerative colitis, and to improving the quality of life in children and adults affected by these diseases.
  - If you’re interested in getting involved and connecting with our local community in person, the closest CCF chapter is the Southwest Ohio/Kentucky chapter, located in Cincinnati.
  - CCF also has local support groups. Go to crohnscolitisfoundation.org/community-support, then click “Find a Support Group”.

- **ImproveCareNow (ICN):** improvecarenow.org
  - ImproveCareNow is a collaborative community where clinicians, researchers, parents and patients are empowered to learn and continuously improve. The goal is to bring reliable, proactive IBD care for healthier children and youth. If you are interested in getting involved in ICN, visit: improvecarenow.org/get_involved_signup

- **Support Groups for patients who have had an ostomy**: Go to: ostomy.org/support-group-finder/

- **Local Medical Legal assistance**
  - Advocates for Basic Legal Equality, Inc. (or ABLE) is a local non-profit law firm that provides legal assistance. Visit them online at ablelaw.org.
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<th>source</th>
<th>information/purpose</th>
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<td>MyMedSchedule.com</td>
<td>Daily medication tracking</td>
<td>secure.medactionplan.com/mymedschedule/</td>
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<tr>
<td>Crohn's and Colitis Foundation</td>
<td>Asks you a few questions about your IBD care and support team. Then connects you with information and resources.</td>
<td>justlikemeibd.org/</td>
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<td></td>
<td>Managing the cost of IBD</td>
<td>site.crohnscolitisfoundation.org/living-with-crohns-colitis/managing-the-cost-of-ibd/</td>
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<td></td>
<td>The main page to access all of Crohn’s and Colitis Foundation’s resources</td>
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<td>GI Kids</td>
<td>Specifically review the “Plowing through the Paperwork” guide under PDF downloads</td>
<td>gikids.org/inflammatory-bowel-disease/ibd-resources/</td>
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<td>ImproveCareNow</td>
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<td>Resources from parents and patients based on what they’ve learned over the years</td>
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<td>Mental Health Toolkit</td>
<td>improvecarenow.org/toolkits_and_guides</td>
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phone apps

All apps are available on Apple and Android devices, unless noted next to the app name.

**My IBD Manager**
Track and store relevant health information between clinician visits, like a food and medication log and pain ratings. This tool was produced by @ Point of Care and the American Gastroenterological Association (AGA).

**Doc4me**
Helps adolescents and young adults search for adult IBD care doctors. The app also gives teens the opportunity to complete checklists for what to know and do to transition to an adult IBD doctor.

**Medisafe**
Add prescriptions and doses and set reminders to take your medications and when you need to refill your medications. You can also download your progress report and send it to your care team as a PDF.

**GI Monitor**
Another app to help patients track their symptoms, such as pain, meals, weight, etc. The data can be downloaded into reports to share with physicians.

**Poop Tracker (available on Android only)**
Poop Tracker uses the Bristol stool scale to determine the quality of your poop and allows you to track and analyze your bowel movement data over time.

**Complete (AbbVie, maker of Humira)**
Resources for managing treatment on HUMIRA are at your fingertips. This app can help you record the locations and dates of your injections, receive medication reminders, log your symptoms and more.

**My Crohn’s and Colitis Team**
MyCrohnsandColitisTeam is a social network and support group for those living with Crohn’s or colitis. Get the emotional support you need from others like you, get practical tips to manage your life with Crohn’s or colitis, and insights about treatment or therapies. MyCrohnsandColitisTeam is the only social network where you can truly connect, make real friendships, and share daily ups and downs in a judgment-free place.

**Oshi**
Track your symptoms and lifestyle factors and get an overall wellness score to help you manage your IBD. You can also read articles about living with IBD, and ask questions to health care professionals and IBD experts.

**myColitis**
Record your bowel movements, symptoms, meals, medications, moods, medical procedures and more. This simple and clean app will make tracking your data an easy habit to start and maintain. Simply tap an icon and fill in the blanks. Take control of your condition by using your data to share with your care team and to better understand your overall health. The app can also track bowel movement discomfort and calculating unique insights.