

Living Well with...



Inflammatory Bowel Disease

*A SELF-MANAGEMENT HANDBOOK FOR
PATIENTS & FAMILIES WITH IBD*

Acknowledgments

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Your IBD Team

Your Name: _____

Parent or Guardian Names: _____

Your IBD Doctor/ Provider: _____

Doctor/ Provider Phone Number: _____

Your Nurse: _____

Nurse Phone Number: _____

Your Surgeon (if you have one): _____

Surgeon Phone Number: _____

Other Team Members (dietitian, social worker, therapist):

Phone Numbers: _____

Pediatrician/ Primary Doctor: _____

Pediatrician/ Primary Doctor Phone Number: _____

School Information: _____

Phone Number: _____



Getting Started

You have been diagnosed with inflammatory bowel disease (IBD). You may feel disappointed, sad, angry or even afraid. You may even blame yourself or other family members. However, it is important to know that this is NOT your fault, and that there are effective treatments for IBD. Finding out what is wrong is just the first step to feeling better. In fact, the majority of people with IBD feel well most of the time, and that is our goal for you!

We have a team of IBD experts who will help take care of you. This team includes doctors, nurses, nurse practitioners, dietitians, psychologists, social workers and researchers. This team also includes another important expert – YOU. In order for us to help you, it is important that we work together.

We are IBD experts, but “you are the expert on you”. That may sound strange, but it’s important! You know yourself better than anyone else. You are the only one who can tell us exactly how you feel. Your parents, doctors and nurses will have an idea of how you are doing, but only you can say for sure how you are feeling. You are also the only one who can do what is needed to stay healthy. Your doctor will give you the best medical advice that he or she can; your parents may remind you to do the things the doctor suggested; only you can actually do them.

Working together, we can come up with the best plan for you, but we all have some work to do. We need to learn about you. You and your family are the best people to teach us. You and your family need to learn about IBD and about our team, and we are here to help you do that. We wrote this book to help you learn about IBD and understand your part on our team. Your participation is very important to us and to your health!

As you begin to look through this book, you will see that all of the sections are similar. Each section will start with “What You Should Expect from Us” and “What We Expect from You”. This will help you know some of the things that you need to do, and what we will do, to make our team as effective as possible.

There is a section on “Why This is Important” to help you understand the reasons for those expectations. An information section then follows. The last two sections are “Let’s Review” and “Things to Do”.

The “Let’s Review” section contains a few simple questions to help you go over the information provided in that section. These questions may seem simple and easy, but they are designed to review the most important points within that section. The “Things to Do” section contains suggestions on specific things that you (and maybe your parents) should do to become a more effective part of our team. We have also included “Personal Action



Plans” at the end of some of the sections to help you set goals for yourself and keep track of your progress. Your healthcare team can help you with this.

We do not expect you to complete or read this book all at once. You should read through and complete the book at your own pace, but try to do at least 1 or 2 sections between visits. You will find that most of them are quick and easy. Certain sections such as the “Food Journal” and the “Growth Log” may be used more often than others. Some sections such as “Surgery” may not apply to you, so you can feel free to focus on the sections that do. Sections such as Transition will only apply as you get older and are preparing to take that step.

Please bring this handbook with you to every visit so that you can show your doctor what things you have done and to help address any concerns or answer any questions.

We started by saying that the majority of people with IBD feel well most of the time. That is our goal for you. We look forward to working closely with you and your family in trying to make this goal a reality.

Understanding Inflammatory Bowel Disease (IBD)

What You Should Expect From Us

- To provide you with basic information about IBD
- To explain the specifics of your disease
- To answer your questions

What We Expect From You

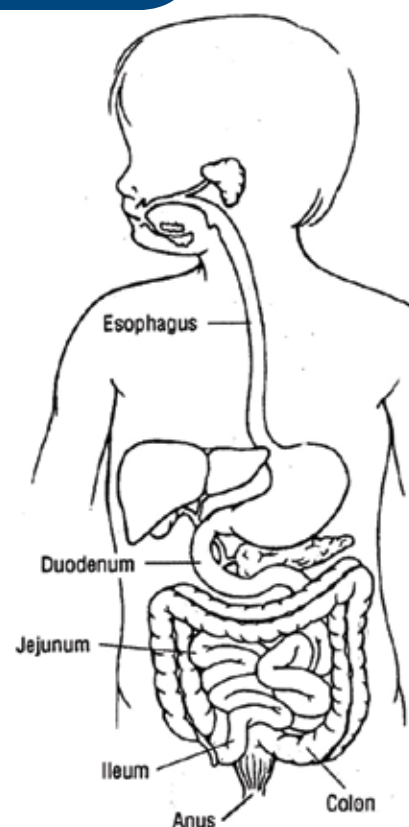
- To have a basic understanding of IBD
- To have a basic understanding of your disease
- Ask questions

Why This is Important

Basic knowledge about inflammatory bowel disease will help you better understand your disease and help you recognize your symptoms. This is very important in managing your disease.

Inflammatory bowel disease (IBD) is a chronic inflammation (irritation) of the intestines that is not due to infection. In IBD, the immune system overreacts and leads to injury of the intestines. There are two main types of IBD: Crohn's disease and ulcerative colitis. Crohn's disease can involve any part of the intestine from mouth to bottom. Ulcerative colitis usually involves only the large intestine (colon).

It is estimated that over 1 million Americans suffer from IBD. IBD occurs in both children and adults. Males and females are affected about equally. IBD is thought to be caused by a combination of both genetic and environmental factors which lead to injury of the intestines. There is a lot of research being done to better understand IBD. Do not confuse IBD with irritable bowel syndrome (IBS). Although the symptoms of IBS are sometimes similar to those of IBD, the disorders have very different causes and treatments.



The gastrointestinal system inside the body.

Signs and Symptoms of IBD May Include:

- Abdominal pain
- Diarrhea or bloody bowel movements
- Weight loss or poor growth
- Fatigue/ Decreased energy level
- Unexplained fevers, joint pains, or mouth sores
- Anemia (low red blood cell count)

Let's Review

1. What are the two main types of IBD? _____ and _____.
2. What are two things that researchers think may play a role in the development of IBD?

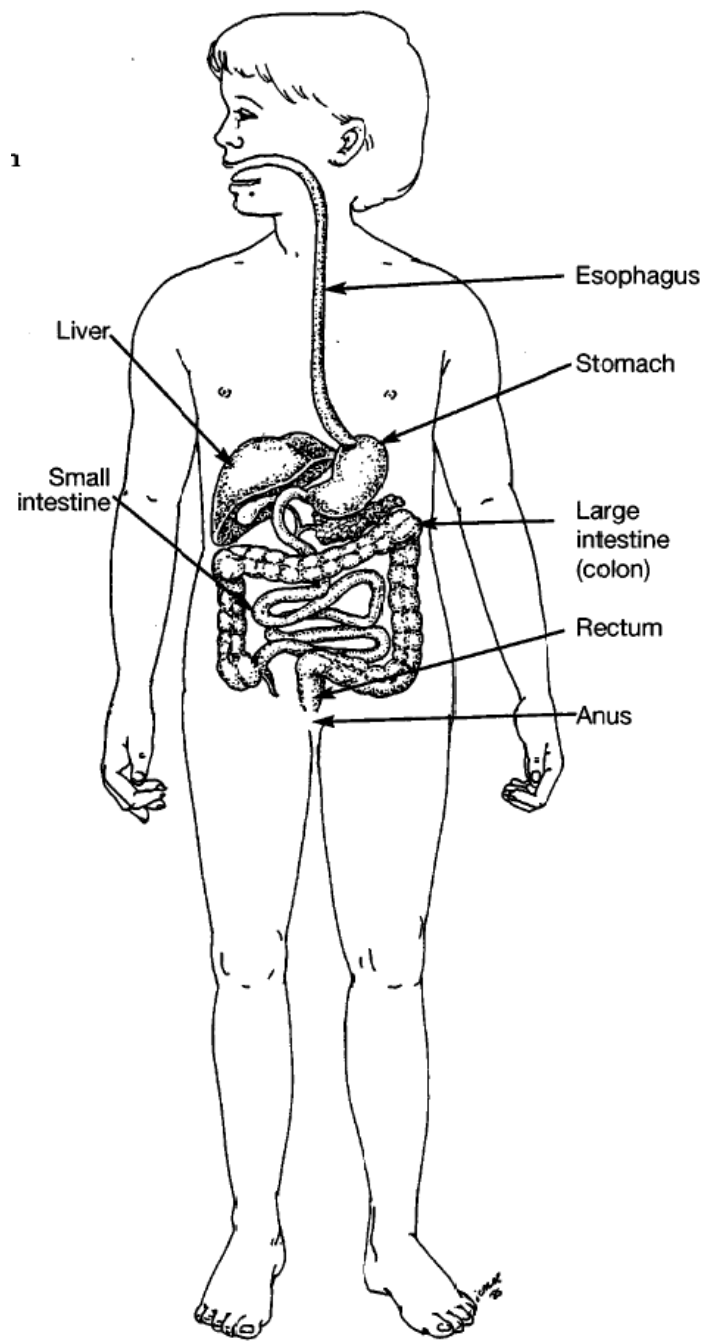
3. IBD is the same as IBS. (circle the correct answer)
☐ True
☐ False
4. Which of the following may be symptoms of IBD?
 - a. Weight loss or poor growth
 - b. Fatigue
 - c. Abdominal pain
 - d. All of the above

Things to Do

- ☐ Review this handbook ____ (patient initials)
- ☐ Review at least one of the websites listed at the end of this book to learn more about IBD ____ (patient initials)
- ☐ Learn about your disease (location, symptoms, etc.) ____ (patient initials)
- ☐ Encourage your doctor or nurse to help you indicate the location(s) of your disease on the diagram on the following page ____ (patient initials)
- ☐ Use the "Office Visit" sheet provided in the following pages to write down questions for your health care provider and keep track of lab results and changes in your care ____ (patient initials)

Your IBD: Where it is Located in Your Body

Diagnosis: _____



When you meet with the doctor or nurse after you are diagnosed, please ask them to tell you the location(s) of your disease. Use the diagram above to mark the areas of your body that are affected. This diagram can be updated if there are any changes in your disease.

Office Visit

This sheet can be copied and used at each office visit to keep track of your disease. Use it to write down questions for your health care provider, and to keep track of lab results, radiology studies, procedures, or changes in therapy. This sheet can also be used to update your primary doctor (ex. pediatrician) about symptoms.

Date: _____

- 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?

Office Visit

This sheet can be copied and used at each office visit to keep track of your disease. Use it to write down questions for your health care provider, and to keep track of lab results, radiology studies, procedures, or changes in therapy. This sheet can also be used to update your primary doctor (ex. pediatrician) about symptoms.

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- 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?

When to Call Your IBD Team

What You Should Expect from Us

- Knowledge of how to identify symptoms of a flare
- Prompt response in treating your symptoms
- Answers to your questions

What We Expect from You

- Identify your symptoms of a flare.
- Call at early signs of onset of symptoms.
The phone number to call is: _____
- Know what medications you are taking and the doses.
- Take your medications consistently and as prescribed by your doctor.



Why This is Important

Even with medical treatment, a person with IBD can experience a *flare*: an episode when symptoms reappear. It is important that you report your symptoms early so that your doctor can provide the best treatment for you. This may help you stay well and prevent some of the complications related to IBD. Avoiding a flare is better than treating a flare. Taking your medications as directed can help control your symptoms and help to avoid a flare.

If you call us for urgent matters, we will contact you within the day. For non-urgent matters we will contact you within 1-2 days. If you need a refill on your prescriptions, please allow 1-2 days for this to be completed.

Alarm Symptoms May Include

- | | |
|---------------------------------------|----------------------|
| • Abdominal pain | • Fevers |
| • Blood in bowel movements | • Joint Pain |
| • Diarrhea/ increased bowel movements | • Fatigue |
| • Nausea/ vomiting | • Change in appetite |

Let's Review

1. A flare is defined as:
 - a. A type of IBD medication
 - b. A period of time when IBD symptoms reappear and become active again
 - c. The place you call when you need a refill
2. Taking your medications as directed may help keep your symptoms under control.
☐ True
☐ False
3. Fill in the blank: Avoiding a flare is better than _____ a flare.

Things to Do

- Call your doctor's office to schedule routine appointments _____ (patient initials)
- Call your doctor's office to alert them of any symptoms and schedule appointments when you are sick _____ (patient initials)



Medical Tests

What You Should Expect From Us

- A complete initial evaluation
- On-going monitoring of your response to treatment
- A complete explanation of your test results

What We Expect From You

- Understand why tests are being done
- Have blood work and other tests completed when requested
- Keep follow-up appointments
- Ask questions



Why This is Important

Testing is important in order to make a diagnosis of IBD, to help us understand what parts of your body are affected, and how to treat you. We also do testing to see if you are having a flare of your disease and to watch for side effects of any medications you may be taking.

Some of the Tests That You May Have Include:

Esophagogastroduodenoscopy (EGD)

An EGD is a test done to examine the lining of the esophagus, stomach, and duodenum (first part of the small intestine). The exam is done with a flexible tube called a *scope*, which has a light and a camera on the end. The doctor will look for redness, swelling, bleeding, ulcers or infections. He will collect small tissue samples called *biopsies* to be looked at under a microscope.

Colonoscopy

A colonoscopy is done to examine the entire colon (large intestine). A flexible tube (*scope*) with a light and camera on the end will be used for the test. The doctor will look for redness, swelling, bleeding ulcers, or infections of the bowel wall. He will collect small samples (*biopsies*) to be looked at under a microscope.

It is normal to feel nervous about the EGD and colonoscopy. These are both very important tools to help diagnose and monitor your disease as needed. The procedures are done under anesthesia so that you will generally not feel anything or remember the procedure. The goal is to gain a better understanding of your disease as safely and comfortably as possible for you.

Here are some helpful hints about what to expect before and after an EGD and/ or colonoscopy.

- You will be asked to not eat or drink for several hours before the procedures. You may also be asked to stay away from red and purple liquids and certain medications such as aspirin and ibuprofen (ex. Advil, Motrin, etc.).
- On the day before a colonoscopy, you will be asked to undergo a “cleanout”. The medications used for this may vary. You must clean out the colon by sticking to a strict diet for at least the day prior to the procedure. You will also be given medications to take to help with the cleanout process. This will all be explained to you and it is **very important** to complete the cleanout in order to ensure a successful procedure.
- Most procedures are same-day, meaning that after you wake up from the sedation/ anesthesia, you can go home.
- Although most patients have no problems after these procedures, you may have some bloating, abdominal cramping or pain, nausea, sore throat, or some blood in your bowel movements. If you have continued blood in your bowel movements, worsening abdominal pain, high fevers, or vomiting, you should contact your doctor or the on-call GI team.

Blood Work

Blood tests are done on a regular basis to keep track of your disease activity and to monitor the effects of your medications. Some common blood tests include:

- Complete blood cell count (CBC) to evaluate for anemia (low red blood cell count), signs of infection, or potential side effects of medications
- Liver enzymes (AST and ALT) to evaluate for potential side effects of medications or complications of IBD
- Erythrocyte sedimentation rate (ESR) and/or C-reactive protein (CRP) to evaluate for inflammation

Stool Studies

When having symptoms of a flare, stool (bowel movement) studies may be done to check for infections or inflammation.

Radiology Studies

These tests help to look for inflammation and check for complications. Examples of these studies include CT scan, MRI, and upper GI series. Your doctor or healthcare provider can explain these to you in more detail if they are needed.

PillCam®

A capsule endoscopy, also known as PillCam, is a test done to look at the esophagus, stomach and small intestine. The procedure involves swallowing a capsule the size of a large vitamin pill. The capsule has its own camera and as it travels through the intestines, pictures are sent to a recorder that you wear on your waist. About 8 hours after the capsule is swallowed, the recorder will be collected. The pictures will then be downloaded to a computer and reviewed. The PillCam is disposable and will naturally pass in a bowel movement.



PillCam recorder belt.

Let's Review

1. Why is testing important?
 - a. It helps make a diagnosis of IBD
 - b. It helps doctors understand which part of the body is affected and choose treatments
 - c. It helps the doctor know if you're having a flare
 - d. It helps monitor side effects of medications you are taking
 - e. All of the above

2. List three tests that you may have done for your IBD.

3. Fill in the blank: A/n _____ is a test done to examine the lining of the esophagus, stomach, and duodenum (first part of the small intestine). A/an _____ is done to examine the entire colon (large intestine).

Things to Do

- ☐ Ask your doctor about the results of your tests and what they mean ____ (patient initials)
- ☐ Ask your doctor what he/ she will learn from the test ____ (patient initials)
- ☐ Check yourself in for a lab or radiology test rather than having your parent do it ____ (patient initials)

Treatments

What to Expect From Us

- Current information about available treatments
- Monitoring for potential side effects related to medication therapy
- Discussion of treatment options, including which options you prefer

What We Expect From You

- Take your medications exactly as they are prescribed
- Let us know if you have any concerns or problems taking your medications or with any of your treatments
- Tell us if you are taking medicines other than those prescribed by your doctor (herbal or alternative medicines/supplements)
- Ask questions

Why This is Important

Listed below are the most common medications used to treat IBD in children, teens, and young adults. Information on non-medication therapies such as nutritional support is also provided. Before starting any treatments, please discuss it with your doctor or health care provider.

Taking your medications for IBD is extremely important. If you take too much medicine, it can be harmful. If you don't take it as prescribed, it may not help you. There are several suggestions offered in the "Adherence" section of this book that help you remember to take your medications. There can be side effects from some medicines although most patients have no difficulties. We check for side effects by doing blood tests and physical exams. That's why going to your clinic appointment and getting your blood tests done is so important!

Medications

Prednisone

Prednisone is a medicine known as a corticosteroid. It is similar to hormones made by the body and helps to reduce inflammation. Prednisone may slow down your body's natural production of these hormones. Because of this, it is important to take the medicine as prescribed and to slowly decrease the medicine as directed. Do not stop it without talking to your doctor. As the dose of prednisone is decreased, the body will slowly begin to make more natural hormones again.



Side effects of prednisone can include weight gain, hunger, and changes in mood and sleep patterns. These usually improve as the dose is lowered. Other side effects can include weakening of the bones, increased risk of infections, high blood pressure, high blood sugar, and stomach irritation. If you take prednisone or other corticosteroids, you should be up to date on vaccines, undergo regular eye exams, and may need to have bone density testing.

Mesalamine

Mesalamine is an aspirin-like medicine which helps control IBD. It can be taken by mouth or can be given by suppository or enema. Some examples of mesalamine products include: Asacol, Colazol, Pentasa, Canasa, Lialda, Apriso and Rowasa.

Rare side effects of these medications include allergic reactions, pancreatitis, and kidney injury. If you are taking these medications, you should wear sunscreen when outside to reduce the risk of skin rashes and sunburns.

6-mercaptopurine (6MP)/Azathioprine

These medications are immunosuppressants. Suppressing the immune system reduces inflammation in the GI tract. These medications do not work right away, so you may need to be on a combination of medications at first.

Blood tests will be done regularly to check for possible side effects, including low white blood count and irritation of the liver or pancreas. Patients taking these medications should be cautious about their amount of sun exposure. They are also at a small increased risk for lymphoma (a tumor of the lymph glands) compared to the average person.

Methotrexate

Methotrexate also suppresses the immune system. It can be given by injection (shot) or by mouth.

Blood tests will be done often to check for potential side effects such as irritation of the liver and low white blood cell count. There is also a small risk of lymphoma. **Pregnant women or women planning to become pregnant should not take this medication.**

Anti-Tumor Necrosis Factor Medications

These medicines include Remicade, Humira, and Cimzia. They block the action of a protein in the body called TNF-alpha (tumor necrosis factor). TNF-alpha is made by the body's immune system. People with IBD may produce too much TNF-alpha which can cause inflammation. Remicade is given as an IV infusion and takes about 3 hours to infuse. The frequency of the infusions depends on your symptoms, but it is usually given every 8 weeks. Humira is given by injection every 2 weeks, and Cimzia is given by injection every month. Before receiving any of these medications, your doctor will test you for tuberculosis.

You will have regular blood tests to monitor for possible side effects, including low white blood cell count, irritation of the liver, infections such as tuberculosis, and a small increased risk of lymphoma (a tumor of the lymph glands).

Surgery

Although treatment with medications is the first option for patients with IBD, some patients may require surgery. Surgery may be needed to address serious IBD complications, or for disease that has not responded to medications. This is further discussed in the surgery section of this book.

Nutritional/ Enteral Therapy

In addition to medications and surgery, there are other treatment options that may be discussed with you, such as a total or partial liquid diet.

This may include taking your liquid diet by mouth, by a naso-gastric tube (a tube that delivers the formula directly into the stomach) or naso-jejunal tube (tube that delivers the formula directly into the intestine.) This type of therapy has been shown to be a safe and successful option in place of medication. This option is further discussed in the nutrition section of this book.

Let's Review

1. Taking your medications the way they are prescribed is important because taking too much can be harmful and not taking them as often as you should may not help you.
☐ True
☐ False
2. List some important health maintenance tasks that patients should complete when taking prednisone: _____

3. Examples of this medication include Asacol, Colazol, Pentasa, Canasa, Lialda, and Rowasa.
 - a. Methotrexate
 - b. Mesalamine
 - c. 6-mercaptopurine (6MP)/Azathioprine
 - d. Remicade
4. This medication is an immunosuppressant that directly affects your immune system and helps reduce inflammation in your GI tract.
 - a. Iron
 - b. Mesalamine
 - c. 6-mercaptopurine (6MP)/Azathioprine
 - d. Antibiotics

Things to Do

- ☐ Develop a plan to help you take your medications exactly as prescribed ____ (patient initials)
- ☐ Bring your medication list or pill containers to each clinic visit ____ (patient initials)
- ☐ Know how to refill your prescriptions and try to do it several times ____ (patient initials)

Self Management Personal Action Plan: Treatments

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Important *Extremely Important*

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Confident *Very Confident*

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
by: _____ (Date) _____ (Name)

E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Self Management Personal Action Plan: Treatments

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Important *Extremely Important*

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all confident *Extremely confident*

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
by: _____ (Date) _____ (Name)

E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Surgery

What You Should Expect From Us

- Your health care team will remain up-to-date regarding the latest surgical treatments
- Meeting with a surgeon if needed so you and your family can learn about options and have the chance to ask questions
- Your IBD and the surgery team will stay in close communication regarding your care
- If you would like, we will put you in touch with other patients who have also had surgery for their IBD
- Discussion of treatment options, including which options you prefer



What We Expect From You

- Let us know if you have concerns about a surgical option
- Let us know if you would like to meet with patients who have had surgery for their IBD
- Be aware of warning/alarm signs and symptoms to look for AFTER a surgical procedure
- Ask questions

Why This is Important

Medications are typically the first line therapy for IBD, and many patients respond well to medical therapy. Some patients however will eventually need surgery. Surgery may be needed if serious complications of IBD develop (see below) or if medications are unable to control symptoms.

Complications of IBD that may require surgery include:

- Intestinal obstruction (blockage in the intestine)
- Uncontrollable bleeding
- Stricture Formation (narrowing of a section of the intestine)
- Perforation of the intestine (tear or hole in the intestine)
- Formation of a fistula (abnormal connection from the intestine to another part of the body) or abscess (collection of pus and inflammation)
- Toxic megacolon (bacteria and gas build up in the intestine causing it to become very dilated or stretched out)

Below is a list of some of the most common surgical treatments for IBD. Before any of the procedures are performed, discuss the benefits and risks of the surgery with your IBD and surgery team.

Common Procedures for Ulcerative Colitis

Proctocolectomy with ileostomy

In this procedure, the colon and rectum are removed (proctocolectomy). A surgically created hole in the abdomen (ileostomy) is made for the removal of stool. After this procedure, an external bag is worn over the hole to collect stool. The ileostomy can be permanent or temporary. Newer surgical techniques have eliminated the need for a permanent ileostomy in many people.

Proctocolectomy with ileal pouch-anal anastomosis (IPAA)

This procedure is performed in two or three stages. The colon and rectum are removed, and a temporary ileostomy (surgically created hole in the abdomen) is made. The ileum (end of the small intestine) is then made into a pouch and connected to the anus. Once this pouch has healed, the ileostomy is closed.

A common complication of this procedure is *pouchitis* (inflammation of this newly formed pouch). This can happen in up to half of patients, and usually occurs in the first one to two years after surgery. Symptoms include, but are not limited to, diarrhea, bloody bowel movements, or abdominal pain. This condition can usually be treated with antibiotics.

Common Procedures for Crohn's Disease

Strictureplasty

This procedure widens a narrowed or tight area of the intestine, and prevents the removal of a section of the intestine. It is most effective in the lower parts of the small intestine (jejunum and ileum).

Intestinal Resection

In this procedure, a section of unhealthy intestine is removed (resection) and the two ends of healthy intestine are joined together (anastomosis). Unfortunately, IBD can reappear at or near the area that was joined together.

Proctocolectomy with ileostomy

This is an option for patients who have severe Crohn's disease that affects their colon. This is described above.

Resources

It can sometimes be difficult to find reliable information on the internet. The following websites contain helpful information:

www.ccfa.org

www.ucandcrohns.org

www.ibdu.org

For more information on any of these topics, ask your healthcare provider.

Let's Review

1. List three potential complications of IBD that may require surgery

2. List one surgical procedure that is common for Ulcerative Colitis

3. List one surgical procedure that is common for Crohn's Disease

Things to Do

- ☐ Review any information given to you by your healthcare team or surgery team regarding surgical options ____ (patient initials)
- ☐ Ask the surgical team questions about possible surgery rather than having your parents do it ____ (patient initials)

Adherence

What You Should Expect From Us

- Our understanding that you are doing your best to manage your condition according to your age and ability
- A non-judgmental discussion of treatment adherence at every visit
- Clear and simple instructions on how to take care of yourself including taking medications and eating the right diet for you
- Tips to help you remember to take your medications or possibly a referral to other resources or health care providers that can help you

What We Expect From You

- Follow the plan that your doctor, nurse practitioner, dietitian, and nurses have developed for managing your condition
- Take your medications everyday as prescribed and get refills in a timely manner so that you do not run out
- Manage your diet according to your dietitian's recommendations
- Let us know when you have difficulties following the plan outlined by your healthcare team so that we can help

Why This is Important

Adherence means how well you follow the medical advice you are given (like taking medicine, making diet changes, exercise). It has been proven that following your healthcare team instructions for managing your condition can help you stay healthier and symptom-free. Taking your medications is particularly important. Studies have shown that patients who do not take their medications have a 30 to 40 percent greater chance of experiencing a flare of their disease.

Many medications can be taken once or twice daily, but certain medications need to be taken more often. If you are on one of the medications that need to be taken more often, you can talk to your doctor about trying to simplify your schedule. We realize that you are very busy with school, work, sports, and other activities and that it can be easy to “forget” or “miss” doses of your medications. In fact, it is very common for patients to miss doses, so you should not be worried about talking openly with your healthcare team about any problems you are having taking your medications. This is an important part of your care because good adherence is one of the best ways to stay healthy.

Adherence Hints

Here are a few helpful hints. They may help you remember to take your medications and to become more independent in managing your IBD.

- Set an alarm on your cell phone or watch as a reminder to take your medicine.
- Look up **www.mymedschedule.com** (a web site that can send you reminder text messages or e-mail alerts).
- Put medications where you can see them (ex. next to toothbrush or in the kitchen). Include your medications as part of your daily routine. Fit them into your life instead of rearranging your life around them.
- Leave yourself a note on the refrigerator or bathroom mirror (ex. "Take 6-MP with dinner!"), on a calendar or in a daily planner.
- Keep a medication journal or chart and check off when you take each dose. *There is an example of a medication log in this handbook.* This will help you keep track of what you have taken so you don't miss doses or take too many doses.
- Stay organized – Use pill boxes and count out your medications for the whole week.
- Ask for help – Mom, dad, and other family members can help you remember to take your medications. Take on more responsibility as you get older, but recognize when you need help and ask for it.



Let's Review

1. Fill in the blank: _____ refers to how well a person follows the medical advice they're given (like taking medicine, making diet changes, exercise).
2. Good adherence is one of the biggest keys to staying healthy.
 - ☐ True
 - ☐ False
3. List three adherence tips:

Things to Do

- ☐ Identify any problems or difficulties taking your medications and discuss with your doctor ____ (patient initials)
- ☐ The medicine(s) I have the hardest time remembering to take is/are: _____
- ☐ The thing(s) that get in the way of me taking my medications is/are (**BE SPECIFIC** – e.g., soccer practice): _____
- ☐ Choose one of the methods listed above to help remind you to take your medications and do it regularly ____ (patient initials)
- ☐ The adherence hint I will practice is: _____

Medication Adherence Log

[illegible]

Medication Adherence Log

[illegible]

Self-Management Personal Action Plan: Adherence

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Important *Extremely Important*

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Confident *Very Confident*

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
by: _____ (Date) _____ (Name)

E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Self-Management Personal Action Plan: Adherence

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Important *Extremely Important*

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Confident *Very Confident*

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
by: _____ (Date) _____ (Name)

E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Growth and Nutrition

What You Should Expect From Us

- To work with dietitians who are knowledgeable about IBD and who will share information with you related to nutrition and IBD
- To meet with a dietitian at least yearly (or more often if needed)
- To have a team monitor your growth and nutritional status and make recommendations to improve your health
- To receive a copy of a growth chart to track on your own (*included in this book*)
- Referral to a growth specialist if needed



What We Expect From You

- To be honest and open about your eating habits
- To make changes in your diet to improve your health
- To work with the dietitian on establishing nutrition goals
- To monitor your weight and height on your growth chart, and tell us if you have any concerns
- Ask questions

Why This is Important

Good nutrition is an important tool to manage IBD. It supports health, growth and bone strength. A dietitian can give you ideas about how to track your progress; however, it will be up to you to improve your eating habits. Some diets or supplements may interfere with your IBD medications or may not be appropriate for you. It is important to discuss your diet with your dietitian. A growth chart is a way for you to track your growth.

We have included several other tracking sheets that you may find helpful. They include the “Nutrition Teaching Sheet” and the “Nutrition Tracking and Goal Sheet” – both of which may be used when you meet with a dietitian.

We have also provided you with a “Food Journal” to keep track of foods that may cause problems for you. Some patients have been able to identify certain foods which increase symptoms such as abdominal pain, diarrhea, and vomiting. Keep track of these reactions to improve your eating habits.

Let's Review

1. Fill in the blank: A person who can help you monitor and maintain good nutrition and give you ideas about how to track your nutrition progress is a _____.
2. All diets or supplements are safe to take with your IBD medications.
 - ☐ True
 - ☐ False

Things to Do

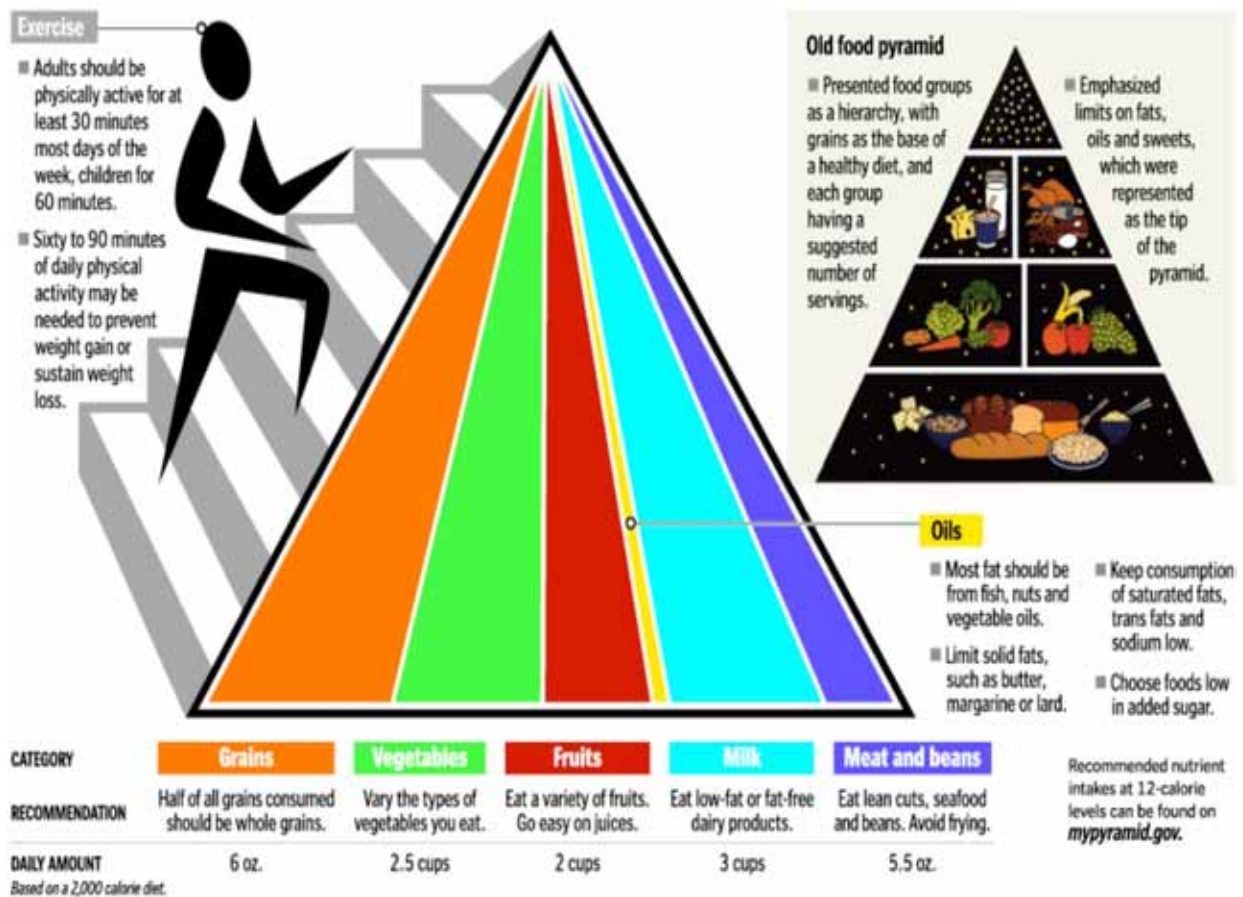
- Read "Eating Well with IBD" found in the following pages ____ (patient initials)
- Complete the quiz at the end of the section ____ (patient initials)
- Learn about what a growth chart looks like and how it is used ____ (patient initials)
- Have your doctor give you an estimate of your growth potential based on your parents' heights and mark it on the growth chart ____ (patient initials)
- Keep track of your height and weight, and let your doctor know if you have any concerns ____ (patient initials)

Eating Well with Inflammatory Bowel Disease

Why Nutrition Is Important

Good nutrition is important in the management of IBD. There are many causes of poor nutrition in children and teens with IBD, such as eating less because of a poor appetite or cramping. The body needs more calories to repair the damage of inflammation. The intestinal tract may not be able to absorb nutrients properly during a “flare”.

The food guide pyramid (see below) is the preferred model of good nutrition. In 2005, the food guide pyramid was revised to include more whole grains, a wider variety of fruits and vegetables, low- fat dairy and meat items, and lower trans- and saturated fats. It also recommends levels of physical activity. The government website www.mypyramid.gov is an interactive website to find “MyPyramid Plan”. Enter your age, weight, height, and activity level to tailor your personal food guide.



Which Foods are Important

Kids and adolescents grow quickly and need well-balanced nutrition. The 4 major nutrients are protein, fat, carbohydrates, and water.

Protein is important for healing and repairing body tissues. Fat is a very concentrated calorie source. It can add calories when your appetite is low and you are eating less. Carbohydrates are the main energy source for the body and, if eaten in appropriate amounts, can help protein repair body tissue. Water is very important during bouts of diarrhea. Drink more water if you have diarrhea to prevent dehydration. An increased amount of protein and water are needed to combat inflammation.



Special Diets for IBD

It is a myth that there are foods that can “cause” or that may “fix or cure” IBD. There is no evidence that any food or diet can “trigger” a flare or cause a remission. Some patients do not have any problems with foods, while others may have difficulties. A food journal is useful to determine food intolerances. Special diets make claims of curing or improving IBD. These claims have not been medically proven and may not be appropriate for you. Some diets, if under medical supervision, may be safe; therefore, it is important to discuss any possible changes with your doctor and dietitian. It is especially important not to automatically remove foods or entire food groups from your diet to try to prevent symptoms of cramping or diarrhea. If some food groups are taken out of the diet completely, vitamin or mineral deficiencies occur.



There may be specific times when monitoring intake of certain foods may be useful:

1. After surgery or if the intestine is narrowed by inflammation, foods that are high in fiber may cause pain and block the intestine. A low-fiber diet may be helpful until the inflammation has improved. Your doctor or dietitian will let you know if you need a low fiber diet.
2. Salt intake should be monitored while on corticosteroids. Salt increases fluid retention (swelling), a side effect of steroids.
3. Some people may not tolerate milk or other dairy products. This is usually a temporary problem. Dairy products are a great source of protein, calcium and vitamin D, and should only be restricted if they cause problems.

All dietary changes should be discussed with a dietitian to ensure that you are still getting the right amount of nutrients.

During a period of inflammation, a diet high in calories and protein may be helpful if you are experiencing weight loss and/or feeling tired. The meat and dairy food groups are a good source of calories and protein. For patients having difficulty eating, liquid supplements can be useful. These liquids may need to be given with a temporary feeding tube to give you the calories needed to ensure good growth.

Your doctor may discuss a treatment option that involves using liquid supplements as the primary or only source of nutrition. The use of total or partial liquid diets has been researched in several studies. Total or partial liquid diets may be as effective as using steroids, may improve growth, and may be effective in preventing flares of IBD. If you are interested in this type of nutrition treatment, ask your doctor and dietitian for more information about it.

Vitamins and Minerals

Vitamins and minerals are important for bodies to work properly and perform daily tasks. There are some vitamins and minerals that may be affected by IBD and some that may need to be increased during times of inflammation.

Calcium

Research has shown that individuals with IBD are at risk for osteoporosis (a condition that leads to thin, weak bones). This may happen for several reasons: (1) Decreased amounts of calcium and vitamin D due to not eating or drinking enough dairy products, (2) improper intestinal absorption and/or (3) long term steroid therapy.

Steroids may interfere with the body's ability to absorb calcium. Eating the recommended amounts of dairy products and/or taking vitamin and mineral supplements can help prevent weak bones.

Recommendations for intake of Calcium:		Sources of Calcium per serving:	
0-6 months	210 mg	Milk (1 cup)	300mg
7-12 months	270 mg	Yogurt (8 oz)	400mg
1-3 years	500 mg	Soy Milk (1 cup)	300mg
4-8 years	800 mg	Fortified cereal (1 cup)	1000mg
9-18 years	1300 mg	Cheese (1.5 oz)	300mg

Vitamin D

Vitamin D deficiency is common in patients with IBD, even when your disease is in remission. It is unclear exactly why this is so common, but it is probably a combination of low vitamin D intake, poor absorption of vitamin D, and decreased time spent outdoors. Just like calcium deficiency, vitamin D deficiency can be associated with increased risk of osteoporosis. Your doctor may check your vitamin levels and may recommend supplements.

Folic Acid

Folic acid deficiency can occur because of decreased appetite or decreased intake of foods containing folic acid, or because certain medications can interfere with its absorption. Meats, breads and cereals, and dark green leafy vegetables are high in folic acid. Your doctor may recommend additional folic acid supplements.

Iron

Iron deficiency can occur if you have ongoing blood loss from the intestines. This may lead to anemia which can cause fatigue or weakness. Increasing foods in your diet which contain iron is important. These foods include meats, fortified breads and cereals, and some fruits and vegetables like raisins, spinach, and bananas. Your doctor will be checking for anemia and may recommend an additional iron supplement. Iron supplements work best when taken with Vitamin C, such as a glass of orange juice.

Multivitamins

Since eating less and intestinal inflammation may reduce your intake and absorption of other vitamins and minerals, a “complete” multivitamin and mineral supplement is usually recommended. Each multivitamin and mineral supplement is different. It is important to check the label to make sure that the key vitamins/minerals are in the supplement (vitamin D, Calcium, Folic Acid, Zinc, and Iron) and that most of each of the nutrients in the supplement supply 100 percent of recommended amounts.



Complimentary and Alternative Medicine (CAM)

Surveys have reported that anywhere from 21 to 68 percent of patients with gastrointestinal diseases have used some method of CAM, including herbs, fish oil, and probiotics. There is limited information on the short and long term effects of these therapies, however. There is also limited scientific evidence on their safety and efficacy. It is important to speak with your doctor and dietitian about any herbal supplements you currently use or are thinking about using. Some herbs may interact with your medications or may worsen IBD symptoms so it is important to discuss all additional medicine practices with the medical team.

There are some substances that may treat the symptoms of IBD.

Fish Oil

Fish oil has anti-inflammatory actions and has been proven to be effective in the treatment of a number of inflammatory diseases. There have been several studies using fish oil in adults with IBD with varying results. The research is ongoing. Until recommendations are established, it may be helpful to eat 2 servings of fish per week for good heart health.

Probiotics

Probiotics are supplements that have been well-researched. Probiotics are micro-organisms present in the gastrointestinal tract that may benefit certain health conditions. There is promise in the use of probiotics with ulcerative colitis and pouchitis; less so for Crohn’s disease. So far, probiotics appear to be safe; however, it can be difficult to find a supplement source with live bacteria. Therefore, it may be beneficial to eat yogurt more often (if tolerated) for not only the probiotic bacteria, but also as a good source of protein and calcium.

Others

You may come across information about other special diets. You may get this information



from people you know, or you may find some of it on the internet. For example, the soothing properties of aloe and coconut oil have been suggested as helpful in IBD. Most recently, a semi-vegetarian diet has been found to be potentially helpful in patients with Crohn's disease. Before starting any special type of diet, you should discuss this with your healthcare provider. Also, start only one new thing at a time. This makes it easier to identify any benefits or potential side effects. Keep track of how you respond to foods in the food journal provided

Resources

Finding good sources of information may be difficult. If looking for information on the internet, look for websites that end with ".gov" or ".org". These websites are monitored closely and are sponsored by trustworthy organizations. The following websites contain helpful information:

www.ccfa.org

www.nih.gov

www.kidsibd.org

For more information on any of these topics (or other nutrition topics which have not been discussed), speak with your doctor and GI dietitian.

Let's Review

1. What are the four major nutrients?

2. There is evidence that certain foods or diets can “trigger” a flare or can bring on a remission.

- ☐ True
- ☐ False

3. All of the following are important vitamins and minerals except:

- a. Folic acid
- b. Carbohydrates
- c. Vitamin D
- d. Calcium



Nutrition Teaching Sheet

Good nutrition is important for the management of inflammatory bowel disease (IBD). You should expect to see a dietitian after diagnosis, at your first 6-month appointment, and yearly thereafter. A dietitian will also be available to see you as needed. If you would like to speak with a dietitian at your next GI appointment, call the dietitian before your appointment to let them know when you are coming or ask to see a dietitian when you are registering.

Initial teaching date:

First part of education (The Basics) – complete

Dietitian _____

Age Appropriate Nutrition

Role of Carbohydrates, Protein, Fat, and Water

Role of Vitamins and Minerals

Potential diet changes

1st biannual visit date:

Second part of education (Beyond the Basics) – complete

Dietitian _____

Partial or total liquid diet

Potentially helpful foods/food parts

Potentially harmful herbs/supplements

Visit date:

Additional Topics discussed:

Dietitian _____



Visit date:

Additional Topics discussed:

Dietitian _____

Visit date:

Additional Topics discussed:

Dietitian _____

Visit date:

Additional Topics discussed:

Dietitian _____

Visit date:

Additional Topics discussed:

Dietitian _____



Visit date:

Additional Topics discussed:

Dietitian _____

Visit date:

Additional Topics discussed:

Dietitian _____

Visit date:

Additional Topics discussed:

Dietitian _____

Nutrition Tracking and Goal Sheet

This sheet can be used each time you meet with the dietitian.

Name: _____

Today's date: _____ weight: _____ height: _____ BMI: _____

Your Nutritional Status today:

- ☐ Outstanding
- ☐ Adequate
- ☐ At Risk
- ☐ Below Acceptable

Nutrition Goals:

- ☐ Gain weight
- ☐ Decrease weight
- ☐ Maintain weight
- ☐ Improve eating habits
- ☐ Increase days taking multivitamins

Plan discussed for reaching goal:

1. _____
2. _____
3. _____

Current diet history reviewed

- ☐ Food record completed ahead of time
- ☐ Food record to be completed
- ☐ Nutrition Supplements recommended

Dietitian: _____

Date of review: _____

☐ Met ☐ Not met

Nutrition Tracking and Goal Sheet

This sheet can be used each time you meet with the dietitian.

Name: _____

Today's date: _____ weight: _____ height: _____ BMI: _____

Your Nutritional Status today:

- ☐ Outstanding
- ☐ Adequate
- ☐ At Risk
- ☐ Below Acceptable

Nutrition Goals:

- ☐ Gain weight
- ☐ Decrease weight
- ☐ Maintain weight
- ☐ Improve eating habits
- ☐ Increase days taking multivitamins

Plan discussed for reaching goal:

1. _____
2. _____
3. _____

Current diet history reviewed

- ☐ Food record completed ahead of time
- ☐ Food record to be completed
- ☐ Nutrition Supplements recommended

Dietitian: _____

Date of review: _____

☐ Met ☐ Not met

Food Journal

You may find that certain foods cause problems such as increased abdominal pain or diarrhea. Use trial and error to determine your individual tolerance. Do not be afraid to try foods you like. This sheet can be used to keep track of those foods and the reactions/symptoms that occur.

Type of Food	Date Food was Tried	Symptoms/Reactions

Food Journal

You may find that certain foods cause problems such as increased abdominal pain or diarrhea. Use trial and error to determine your individual tolerance. Do not be afraid to try foods you like. This sheet can be used to keep track of those foods and the reactions/symptoms that occur.

Type of Food	Date Food was Tried	Symptoms/Reactions

Growth Log

This sheet can be used to keep track of your weight and height at each visit. These numbers should also be plotted on the growth curves provided. You can also keep track of your disease activity at the time that the weight and height were taken.

Date	Height	Weight	Disease Activity

Growth Log

This sheet can be used to keep track of your weight and height at each visit. These numbers should also be plotted on the growth curves provided. You can also keep track of your disease activity at the time that the weight and height were taken.

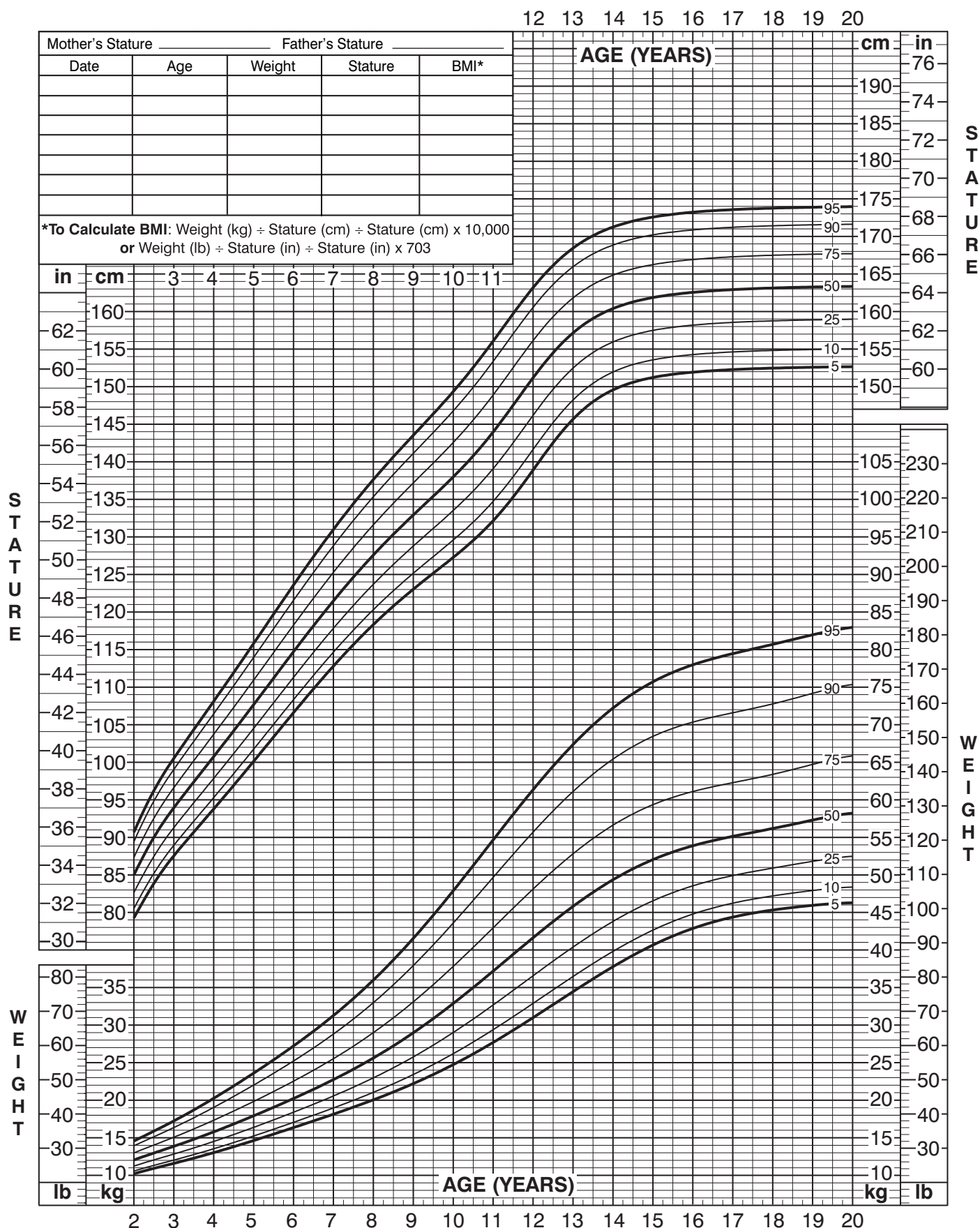
Date	Height	Weight	Disease Activity

2 to 20 years: Girls

Stature-for-age and Weight-for-age percentiles

NAME _____

RECORD # _____



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>



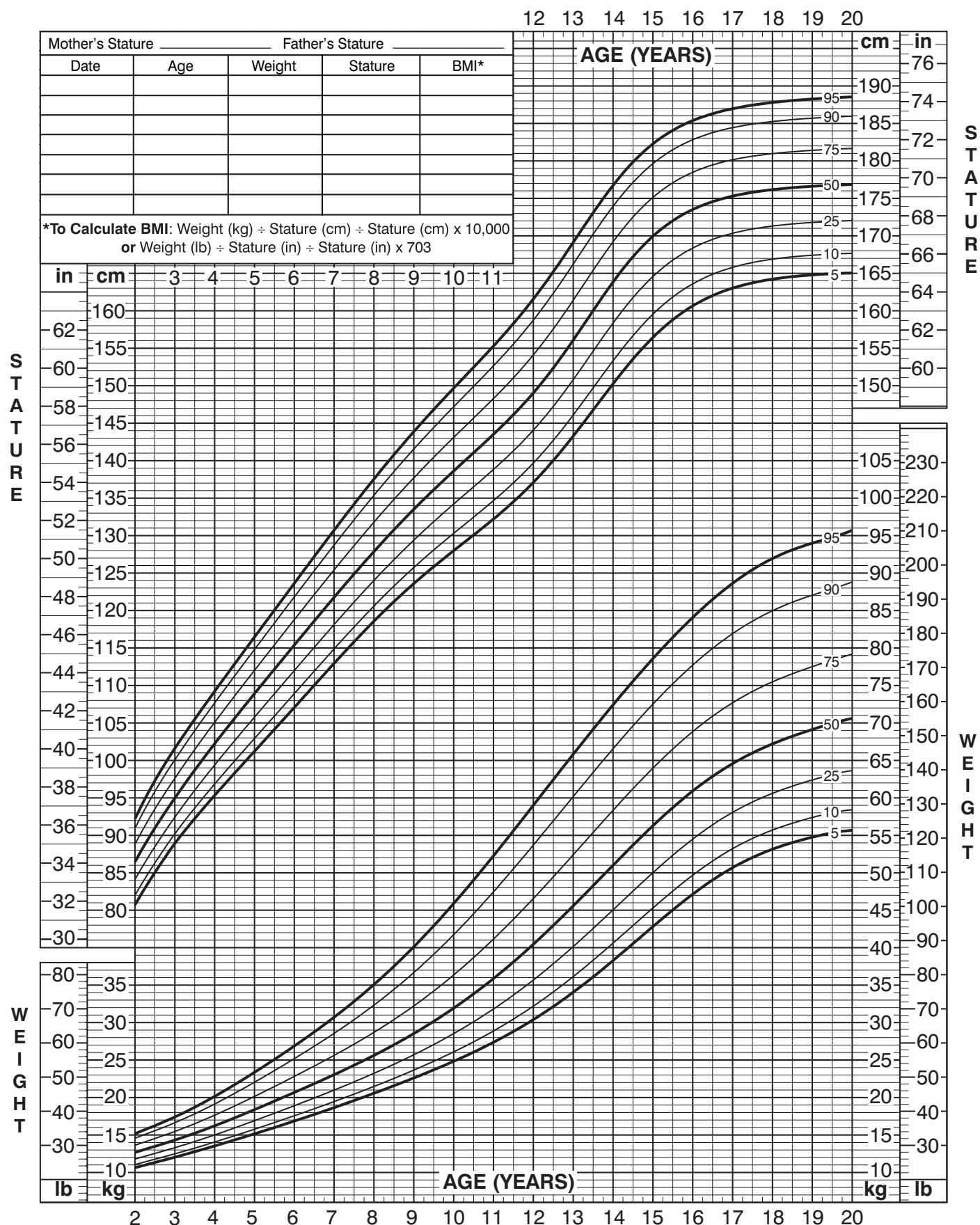
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2 to 20 years: Boys

Stature-for-age and Weight-for-age percentiles

NAME _____

RECORD # _____



Published May 30, 2000 (modified 11/21/00).

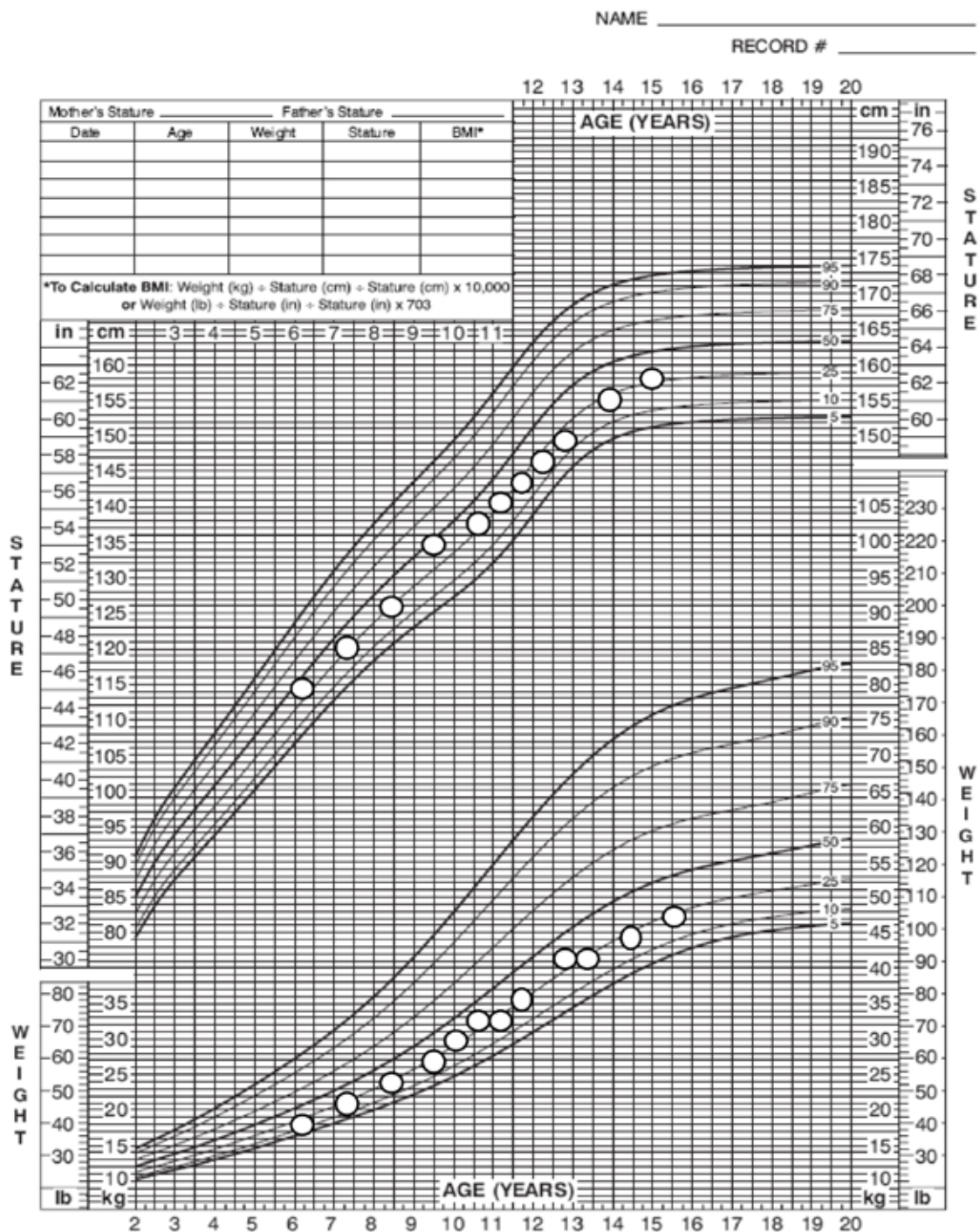
SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).
<http://www.cdc.gov/growthcharts>



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Sample Growth Curve

This is a sample growth curve of a healthy patient. Height and weight are tracked from ages 6 to 16. This patient remained at approximately the 25th percentile

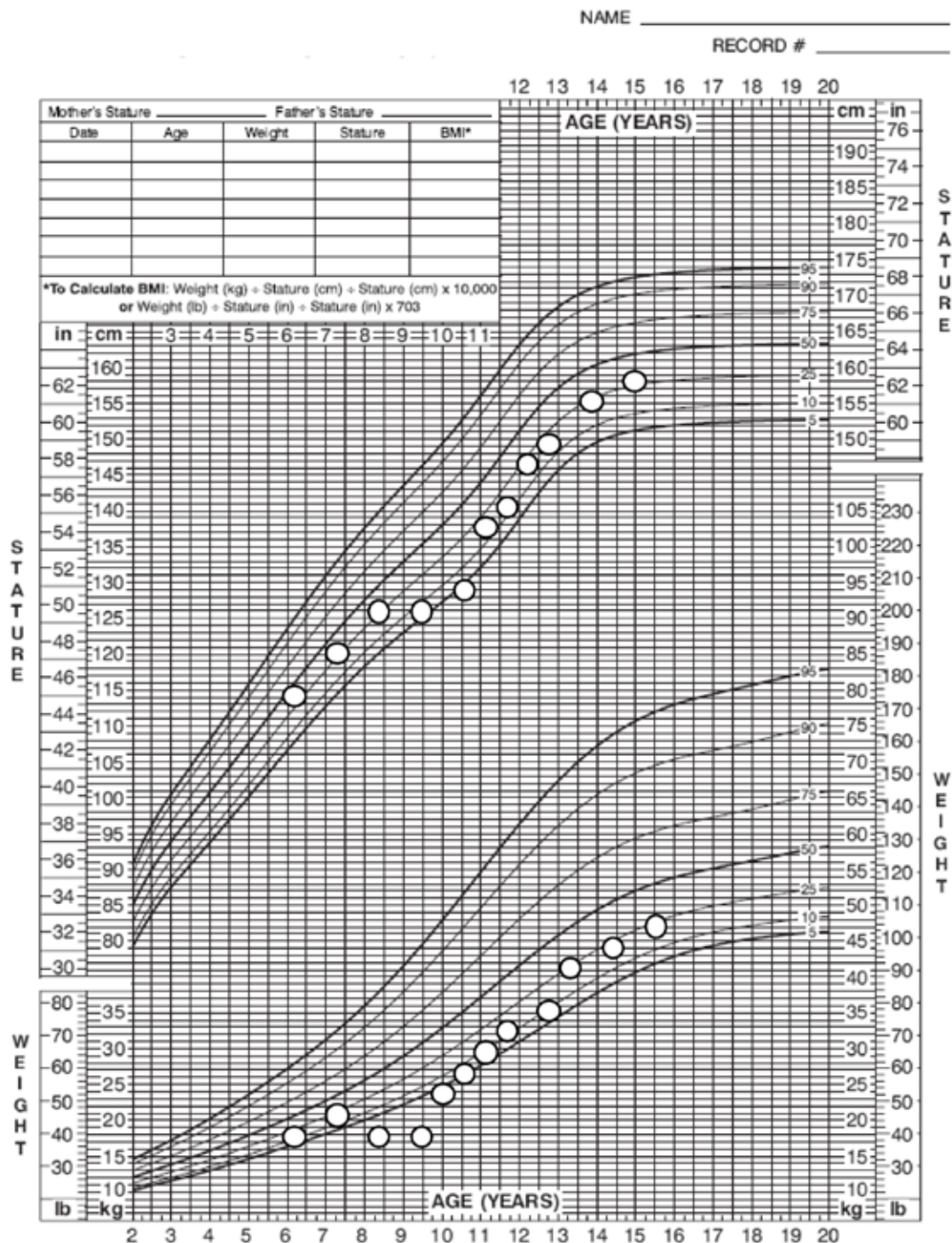


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the National Center for Chronic Disease Prevention and Health Promotion (2000).
<http://www.cdc.gov/growthcharts>



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This individual started having symptoms of IBD at approximately 8 years old. IBD was not diagnosed until age 10. At that time she started on medicines and began to eat better. As a result her weight and height improved.



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.odc.gov/growth-charts>



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Self Management Personal Action Plan: Nutrition

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Important *Extremely Important*

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Confident *Very Confident*

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
by: _____ (Date) _____ (Name)

E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Self Management Personal Action Plan: Nutrition

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0	1	2	3	4	5	6	7	8	9	10
<i>Not at all Important</i>						<i>Extremely Important</i>				

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0	1	2	3	4	5	6	7	8	9	10
<i>Not at all Confident</i>						<i>Very Confident</i>				

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
by: _____ (Date) _____ (Name)

E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Vaccinations

What You Should Expect From Us

- To inform you which vaccines are safe for you to receive
- To work with your primary doctor to be sure that you have received all your vaccines
- To let you know if any new vaccines are needed

What We Expect From You

- To keep your vaccines up to date, including your yearly flu vaccine(s)
- To keep track of your vaccines. Your primary doctor should have a list of these since most of them are received during childhood
- Ask questions

Why This is Important

Patients with IBD should receive vaccines on the same schedule as other children. This includes a yearly flu vaccine. This is particularly important because many of the IBD medications can suppress or slow down the immune system.

Infections can be more serious for patients that are taking these medications.

If you are taking medications that affect your immune system, you should not receive live-virus vaccines such as the nasal flu-mist and the chickenpox vaccine.

For more information, please discuss this with your doctor or visit the National Immunization Program website at www.cdc.gov/nip.



Let's Review

1. Vaccines are particularly important for patients with IBD because many IBD medications can suppress the immune system and infections can be more serious.
 - ☐ True
 - ☐ False
2. Live-virus vaccines should be avoided in patients taking _____ medications.
 - a. Antibiotics
 - b. Vitamins
 - c. Immunosuppressant

Things to Do

- ☐ Remind your doctor that you need a yearly flu vaccine ____ (patient initials)
- ☐ Make sure your vaccine record is up-to-date ____ (patient initials)

Psychosocial Issues

What You Should Expect From Us

- To talk to you and listen to your opinions and concerns.
- To check in with you about stress, feelings/emotions, school issues, social concerns, and difficulties with any aspect of your care (like taking your medicines).
- Access to a psychologist and/or social worker who can talk to you in clinic or a referral to a therapist if needed to help you overcome any difficulties you may be having.

What We Expect From You

- Open and honest communication about how you are feeling
- To let us know if you are having difficulties dealing with your IBD
- Tell us when there is stress or other difficulties in your life
- Keep appointments with therapists
- Ask questions – there are no wrong questions, and it's good to have lots of questions

Why This is Important

We are not only interested in your IBD – we are interested in you as a person too. Having IBD can be hard at times, and we want to help you with all aspects of your life that can be affected by IBD. It is stressful dealing with a chronic illness, visiting the doctor's office often, and remembering to take all your medications, all while just trying to live a "normal" life. Patients with IBD may be embarrassed by their symptoms or the frequent need to use the bathroom. They may feel uncomfortable talking to their friends or family about their disease and can often feel like an outsider. A lot of research has shown that psychological issues like stress and sadness can affect medical conditions. It is important to remember that it is NOT YOUR FAULT that you have been diagnosed with IBD. Addressing your psychological or emotional concerns might actually help your IBD!

What Therapists Do

Therapists can help kids adjust to life with IBD.

They can help answer questions like:

- Who should I tell about my IBD? How should I tell them? What do I say if they ask questions?
- What do I do if I have to go to the bathroom A LOT at school?
- What do I do if I'm having pain at school?
- What if I've missed a lot of school, and I'm having a hard time going back?
- Any other questions about life with IBD.



Therapists can also help with stress management, pain management, taking medicine (such as learning how to swallow pills and remembering to take medicine), depression, anxiety, and other emotional issues. Therapists can work with your school to get you your own permanent bathroom pass and access to a good bathroom. They can work with the school to help you transition back if you have missed a lot of time at school. They can help you cope with pain when you're not home and help you maintain a social life when you are having a flare.

A therapist usually meets with you for 45–50 minutes. Parents can be involved, too. Depending on your schedule and needs, you might meet with a therapist every week or every other week. You might be able to coordinate your therapy sessions with your Remicade infusions and/or GI appointments. We also know therapists outside of the hospital and can connect you with them if needed.

Coping with Stress

Here are some things to keep in mind to help you cope with stress:

- Be realistic about your workload. It is important not to take on too many responsibilities with school, work and extracurricular activities.
- Exercise and follow a good diet.
- Get enough sleep. (recommend at least 8 hours per night).
- Write in a journal.
- Talk to someone, such as a therapist, parent, sibling, teacher, or friend if necessary.
- Use relaxation techniques such as those listed below.
 1. **Deep breathing:** Close your eyes and take slow deep breaths through your nose. Exhale slow and long breaths through your mouth. Repeat.

2. **Guided imagery:** Close your eyes and take deep breaths in and out. Visualize yourself in a relaxing and happy place (like at the beach). Focus on what/who you see? Hear? Smell? Touch?
3. **Meditation:** Close your eyes and take deep breaths in and out. Choose a positive, relaxing self-statement (like “Relax” or “Breathe”) and repeat this statement to yourself slowly (“relax...relax...relax”). Keep breathing in and out.

These techniques can help manage mild to moderate pain. But you should always call your healthcare team if you have significant pain or pain that doesn’t go away.

Lifestyle

You can live a normal life with IBD. Patients with IBD go to college, play sports, have jobs, and are able to participate in almost all activities. Patients can go on to have normal romantic relationships, and most people with IBD can have children as well, since fertility is rarely affected.

You will also likely be faced with decisions about other things such as smoking and alcohol use. All of these issues should be discussed openly and honestly with your doctor. The best advice is to never start smoking. For those who have started smoking, there are many resources to help you quit. Smoking can affect both Crohn’s disease and ulcerative colitis. Patients with Crohn’s disease who smoke may not respond as well to treatment, they may relapse, and they may have a higher risk for surgery. Alcohol should only be consumed when you reach the legal age limit and should not be consumed in excess. Some patients report that drinking alcohol makes their IBD symptoms worse. It is especially a problem when taking certain medications such as Flagyl because it can lead to severe nausea and vomiting. Always check with your doctor to see if it is safe to drink alcohol while taking medications.

Managing school work can also be difficult when dealing with a chronic illness such as IBD. Doctor’s appointments and flares may lead to missed school days. Teachers and school administrators may not fully understand your disease. There are several resources that may be helpful to address these concerns. For example, an individualized educational plan (IEP) or a 504 plan can be developed with the help of your school to address any concerns. These issues should be discussed with your doctor or social worker. More information is available on www.ccfa.org and www.ibdu.org.

Privacy is another concern for many patients with IBD. It can be difficult to explain your disease to your friends, other family members, or school or work colleagues. You do not have to tell anyone about your disease, but it is helpful to have at least 1 or 2 people with whom you feel comfortable talking. There is no “right way” to talk to your friends about IBD. Tell them whatever you are comfortable telling them. Some people tell their



friends that they have a “stomach problem” that makes them need to go to the bathroom more often. They tell them they need to take medication for it. Others tell their friends more details about what IBD is and how it affects them. Your friends should know that they cannot “catch” IBD from you and that it is safe to play or hang out with you.

There are also opportunities to share your stories with other children and teens with IBD. The Crohn’s & Colitis Foundation (CCFA) has local chapters across the country. The CCFA offers both educational programs and support groups. CCFA also sponsors Camp Oasis, a summer camp for children and teens with IBD.

Let's Review

1. What are three relaxation techniques to help you deal with stress caused by your IBD symptoms?

2. Therapists can help you and your family by working with your school to get you your own permanent bathroom pass and access to a good bathroom, as well as work with the school to help you transition back if you've missed a lot.

- ☐ True
- ☐ False

3. Fill in the blank: You can live a _____ life with IBD.

Things to Do

- ☐ Pick one or two of your favorite ways to deal with stress and do them regularly ____ (patient initials)
- ☐ The relaxation strategy I will practice when I'm stressed is: _____
- ☐ Identify at least one person that you trust and can talk to, and tell them what things you worry about ____ (patient initials)
- ☐ I worry about: _____

- ☐ The person I trust and can talk to is: _____
- ☐ Tell your doctor about any concerns that you have about IBD ____ (patient initials)

Self Management Personal Action Plan: Psychosocial

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Important *Extremely Important*

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Confident *Very Confident*

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
by: _____ (Date) _____ (Name)

E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Self Management Personal Action Plan: Psychosocial

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

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3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
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- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

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6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
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Reviewed By _____ Date _____

Transition: Responsibilities and Expectations

What You Should Expect From Us

- To talk to you and listen to your opinions about when and how to switch to an adult gastroenterologist
- To allow you to make choices about your care
- To help you learn the skills you need to take care of your medical needs

What We Expect From You

- Take responsibility for your health
- Use the skills that we teach you
- Ask questions



Why This is Important

When we talk about self-management and transition, we are talking about the process of learning to be independent and to take care of yourself. Some adolescents with IBD will switch from a pediatric to an adult gastroenterologist. Even those patients who continue to go to their pediatric specialist will need to switch from dependence on their parents or caretakers to independent self-management. This process can be scary and difficult if you are not prepared. Transitioning is a long-term process and does not happen overnight. Transitioning to adult health care and becoming responsible for your own health can take anywhere from several months to over one year. It is important that this process is done when you are ready.



Key areas that should be discussed for successful self-management and transition include:

- **Knowledge**
 - Disease
 - Medications (name, dose, purpose, side effects)
 - Lab/ radiology tests
- **Independence and Assertiveness**
 - Independent health behaviors (responsible for medications and office visits)
 - Self-advocacy (speaking up for yourself at school or work)
 - Insurance issues
- **Lifestyle**
 - Effects of smoking and alcohol
 - Consequences of not taking medications
 - Fertility and sexuality

The exact age at which these areas are discussed can be different based on maturity level and support system. All of them, as well as any other questions, should be discussed openly with your doctor.

Experts who help adolescents transition to adult care have developed different checklists to help you and all of us on your team work through this process. (See following pages)

The website **www.ibdu.org**, a site for older teens with IBD, is also very helpful. It includes information about IBD, tips on diet and stress-relieving techniques and methods of dealing with IBD at college or work. This website is a great resource for patients in the transition process. You also have the opportunity to read other patients' stories and share your own.

Let's Review

1. Transitioning from a pediatric to adult gastroenterologist is a long-term process, not something that happens overnight. It is important that this process is done when you are ready.
 - ☐ True
 - ☐ False
2. All of the following are key areas that should be addressed for successful self-management and transitions, except:
 - a. Lifestyle
 - b. Age
 - c. Knowledge
 - d. Independence and Assertiveness

Things to Do

- ☐ Complete the Patient Transition Checklist on the following page and remind your doctor to review the checklist with you ____ (patient initials)
- ☐ Continue to update the checklist until you are able to check off the column for "I can do this by myself" for all the items listed ____ (patient initials)
- ☐ Complete the Responsibilities Worksheet to help you develop an action plan and have your doctor review this with you ____ (patient initials)

Patient Transition Checklist

Please answer each item below by placing a check mark under the column on the right side that indicates whether you do the task by yourself, with some help from others, or cannot do or need lots of help from others. There is no right or wrong answer. Your answers will help us know what we need to do to help you manage your IBD better. You can keep updating this sheet until you are able to check the “I can do this by myself” columns for all items.

	Basic Knowledge About IBD	I can do this on my own with no help from others	I can do this with some help from others	I can not do this or I need lots of help from others
1	I can tell others what my diagnosis is			
2	I can explain how my illness affects my body			
3	I can tell when I'm having a flare-up or when I need to go see the doctor			
4	I can list the foods and/or activities that make me feel bad or uncomfortable			
	Doctor Visits			
1	I can tell others the name of my Gastroenterologist (GI doctor)			
2	I answer question during medical appointments			
3	I ask questions during medical appointments			
4	I feel comfortable talking with my doctors/nurses if I don't like my treatment regimen or have difficulty following it			
5	I tell my doctors/nurses if I don't understand what they are talking about during medical appointments			
	Medication & Other Treatments			
1	I can name my medications and/or treatments			
2	I can tell others when I take each medication and how much			
3	I can tell others why I take each medication			
4	I can get the medications I need when it is time for me to take them			
5	I can make changes to my medications as recommended by my Gastroenterologist (GI doctor)			
6	I can tell others what will happen to me if I do not take my medications correctly			
7	I can tell others what medications I cannot take because they might interact with the medication I already take			
	Disease Management			
1	I tell my parents when I'm running low on medication			
2	I call the pharmacy to get refills on my medications			
3	I call the doctor to schedule my medical appointments			
4	I know what other health services (ex., CCFA, social worker, dietitian, psychologist) are available to me			
5	I can prepare my medication in advance to accommodate long trips, vacations, overnights, etc.			

Responsibility Worksheet

This sheet is another way to keep track of your progress in the main areas involved in transition from pediatric to adult healthcare. Use this to make goals and track your progress with each one. This sheet can be copied and used multiple times.

	Specific Goals and Activities
Basic Knowledge About IBD	<i>Example: Become familiar with what IBD is and what causes it</i>
	Specific Goals and Activities
Doctor Visits	<i>Example: Asking questions during doctor visits</i>
	Specific Goals and Activities
Medication	<i>Example: Filling my pill box with my medications</i>
	Specific Goals and Activities
Other Treatments (Ex. Nutrition, surgery)	<i>Example: Limiting foods that make me feel bad</i>

Self Management Personal Action Plan: Transition

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____ (Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Important *Extremely Important*

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Confident *Very Confident*

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
by: _____ (Date) _____ (Name)

E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Self Management Personal Action Plan: Transition

(Feel free to make extra copies of this sheet for future use)

My Personal Action Plan _____(Name)

Something I want to improve or change (a health goal or other personal goal):

1. How important is it to me to make this change? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Important Extremely Important

2. What might make it difficult for me to achieve my goal (what are the barriers)?

3. Steps I will take to make this change (for example, what, when, how, and with whom):

- a. _____
- b. _____
- c. _____
- d. _____

4. How confident am I that I can carry out this plan? (circle a number)

0 1 2 3 4 5 6 7 8 9 10
Not at all Confident Very Confident

5. Information or support I might need in accomplishing my goal: _____

6. I will know my plan is working when _____

7. I will celebrate my success by _____

I agree to this plan of action and will review my plan and progress on _____ with _____
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E-mail _____ Phone _____

Text message _____ Returning to clinic or other contact _____

Signature _____ Date _____

Reviewed By _____ Date _____

Financial Resources

What You Should Expect from Us

- Information about available resources
- Help with identifying appropriate resources at your request
- Help with obtaining, completing, and submitting paperwork at your request

What We Expect from You

- Identify and express financial concerns
- Initiate the application process when appropriate
- Complete any necessary paper work
- Ask questions

Why This is Important

A diagnosis of a chronic illness can be both emotionally and financially overwhelming for families. It is important that you are aware of the resources available to help you follow your healthcare plan. We want to help you with any financial concerns so that you can focus on staying healthy.

Insurance

Every insurance provider is unique and will cover items differently. This is something that should be checked with your individual insurance.

Supplemental Resources

Some states have supplemental insurance programs or other resources to help patients with chronic health problems. You should check with your state's Department of Health or your social worker to see what options are available.

Your hospital may have additional financial assistance programs which you may find helpful. Feel free to ask your doctor for more information. Ask your nurse or social worker if there are any medication programs that may be helpful to you.

School Financial Aid

Ask your doctor about possible college scholarships for patients with IBD. Their availability varies from year to year.



Let's Review

1. What resources are available to help with financial concerns?
 - a. Medication Programs
 - b. Insurance Providers
 - c. School Financial Aid
 - d. All of the above

Things to Do

- ☐ Review your insurance benefits ____ (patient initials)
- ☐ Verify transition coverage for patients 17-22 years old ____ (patient initials)

Quality Improvement and Research

What You Should Expect from Us

- Interest and participation in quality improvement efforts for patients with IBD
- The opportunity to be aware of or participate in current research
- A complete explanation of research projects if you choose to participate

What We Expect from You

- Follow all instructions outlined in a research study if you decide to participate
- Keep your research study staff informed of any changes in treatments or symptoms
- Ask questions

Why This is Important

Quality improvement and research are very important in improving care and outcomes for patients with IBD. What we learn today from our patients shapes the future for others. Much of what we know about how to treat you comes from what we have learned from treating patients in the past. The success of these studies relies heavily on patients and healthcare staff working as a team.

Quality Improvement

Quality Improvement (QI) is a process of making sure that each patient consistently receives the best possible care. ImproveCareNow (ICN) is an example of an organization dedicated to quality improvement in pediatric and adolescent IBD. ImproveCareNow members are working together to develop uniform guidelines for treatment, share ideas for improvement and raise the level of care provided to all patients.

What Is Research?

Research helps us to understand how and why IBD happens, and how best to take care of people with IBD. There are many types of research such as clinical trials, registries, QI studies and basic science. Clinical trials are studies that compare treatments to see what is safe and most effective. Registries are studies where information, and sometimes blood or other samples, are gathered over time for a large number of people with IBD. Registries can help answer questions such as which patients are at the highest risk of complications of IBD, what treatment strategies are most effective, and whether there are risks to treatments that are currently used. QI research is done to determine the best ways of providing care. QI studies can help answer questions such as how to best use existing treatments and what things can be done to help patients have the best outcomes. Basic science research

is done in a laboratory, and helps us understand the science behind how and why IBD happens.

Your hospital may participate in, or even lead one or more research studies about IBD. You may be asked if you would like to participate. You should know that within each research institution is a group of professionals known as the Institutional Review Board (IRB). The IRB reviews and

approves all research done at that institution to assure that research is conducted according to ethical standards. No research can be started without IRB approval



Let's Review

1. Fill in the blank: A _____ is a study that compares treatments to see which is safe and effective.
3. The Institutional Review Board (IRB) reviews and approves all clinical research done at an institution. No research can be started without IRB approval. _____

☐ True
☐ False

Things to Do

- ☐ If you are interested, ask about research studies in which you may be able to participate ____ (patient initials)

Appendix: Website Sources for Parents and Patients

The Children's Digestive Health and Nutrition Foundation (CDHNF)

www.cdhnf.org

The Children's Digestive Health and Nutrition Foundation (CDHNF) is one of the leading providers of information on pediatric gastrointestinal, liver and nutritional issues, with a primary goal to improve the treatment and management of gastrointestinal diseases in children.

Crohn's and Colitis Foundation of America (CCFA)

www.ccfa.org

The Crohn's and Colitis Foundation of America is a non-profit organization dedicated to finding the cure for Crohn's disease and ulcerative colitis in children and adults.

www.ucandcrohns.org

The CCFA has recently created this website specifically for teens living with IBD. It includes general information about IBD, and allows you to connect with other teens who share their stories and experiences.

Starlight Starbright Programs

www.starlight.org

www.starbrightworld.org

Serving more than 180,000 children each month, Starlight Starbright offers a comprehensive menu of ongoing support for children and families before, during and after medical treatment. Starbright World is an online social network for teens with serious medical conditions such as IBD. It allows you to connect with other teens and share stories, provide advice, or just vent.



National Digestive Diseases Information Clearinghouse (NDDIC) National Institutes of Health

Crohn's Disease

www.digestive.niddk.nih.gov/ddiseases/pubs/crohns/index.htm

Ulcerative Colitis

www.digestive.niddk.nih.gov/ddiseases/pubs/colitis/index.htm

The National Digestive Diseases Information Clearinghouse (NDDIC) was established in 1980 to increase knowledge and understanding about digestive diseases among people with these conditions and their families, health care professionals, and the general public.

IBD University (IBDU)

www.ibdu.org

IBD University is a great resource for tips and information as you transition from pediatric care to adult care. It includes basic information about IBD, insurance questions, information about nutrition and daily living. This website can definitely help you “graduate to independence”.

ImproveCareNow (ICN)

www.improvecarenow.org

ImproveCareNow is a group of healthcare providers, patients, and families dedicated to improving the quality of care provided to children and adolescents with IBD. ImproveCareNow has combined the experience of 30 centers across the country and made it possible for healthcare professionals, patients, and families to openly share information related to IBD for the benefit of all patients.

The information and reference materials included in this handbook are intended to be general information for the reader, and are not intended for diagnostic or treatment purposes. Please consult with your healthcare provider for any specific questions and concerns that you may have, as this information does not replace a visit with your health care team.

