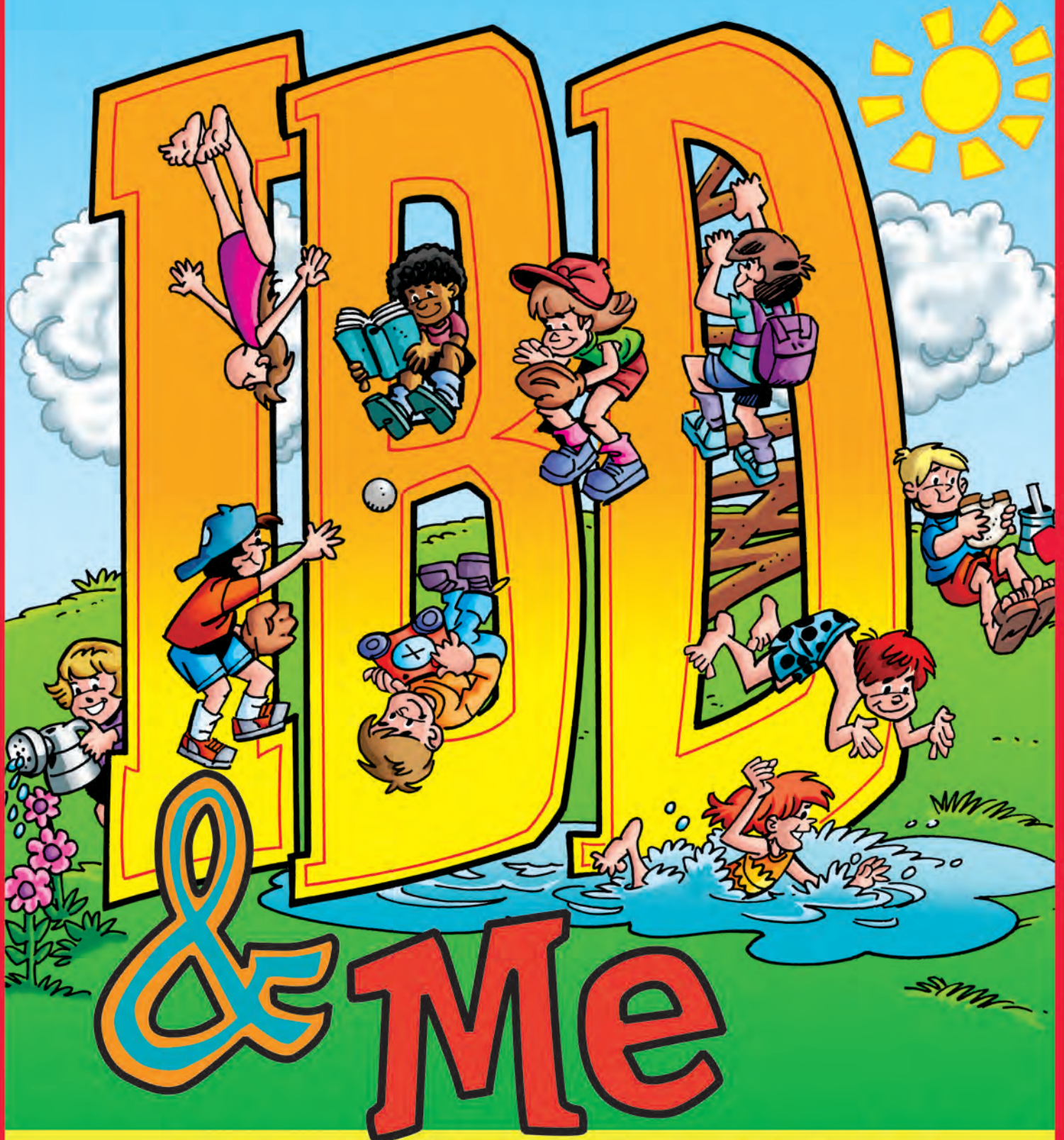




CROHN'S & COLITIS  
FOUNDATION OF AMERICA



& Me

ACTIVITY BOOK

## Hi Kids,

Thanks for reading our activity book, **IBD & ME!** We hope you learn a little more about Crohn's disease and ulcerative colitis and why it sometimes makes you feel sick. Crohn's disease and ulcerative colitis are both sometimes called "IBD" for short, which is easier and quicker to say than Inflammatory Bowel Diseases. Learning more about Crohn's disease and ulcerative colitis can help you learn to get through the day, even when part of you is not feeling so well.

We wrote this book to help you:

- \* understand some of the words you might hear your doctor and parents talk about;
- \* feel less worried and find out ways to deal with what you're going through;
- \* find the right words to tell your friends or your teachers (if you want) about how you're feeling.

You can work on all the activities in the book by yourself, or do the activities with someone else so they can learn about IBD too. Knowing more about IBD is good for everyone, but IBD can be different for different kids. Learning about your own health is one of the best ways to take care of yourself.

*Crohn's & Colitis Foundation of America  
(CCFA)*

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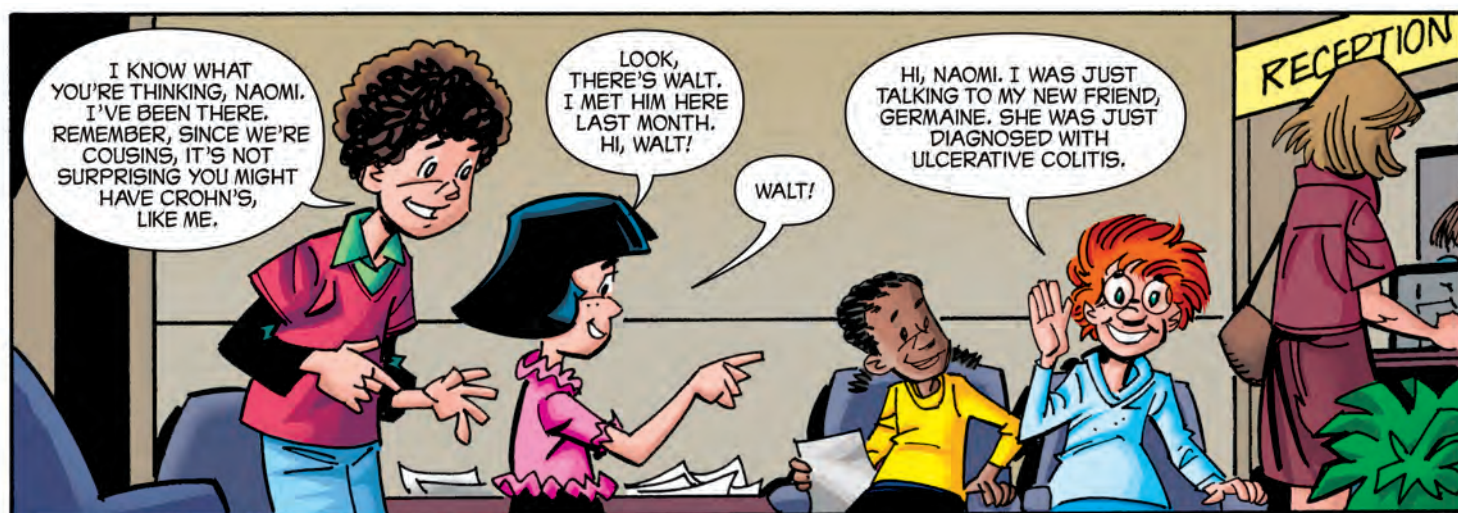
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# A Slice of Life with IBD





# The GI Tract

The **gastrointestinal tract** is the name of the path food takes through your body. The first word is a long one, but is very easy to say. You can say it like it is a lot of little words:

gas trō in test in əl

Most people call the gastrointestinal tract the **GI tract**.

When you swallow food, it moves down the **throat** into the **stomach**.

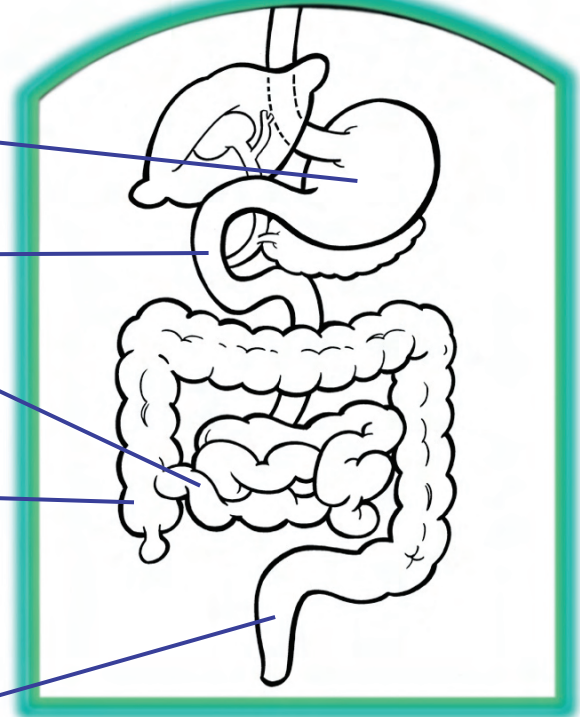
Then it goes into long tubes. The first long tube is called the **small intestine**.

At the end of the small intestine is the **ileum** (il ē uhm). Food goes through the ileum into another tube.

This tube is the **large intestine**.

In the GI tract, chewed up food is **digested**. Food is broken down so the body can absorb, or take what it needs to build and repair itself. What it doesn't use is pushed out as pee or through the **rectum** as a **bowel movement**.

## A healthy GI tract



Can you trace the path that food takes through the GI tract?

Use the information on these two pages to match these key terms with their meaning.

1. **gastrointestinal tract**

2. **bowel movement**

3. **inflamed**

4. **absorb**

a. swollen

b. illness when the GI tract is swollen

c. waste that leaves the body

d. the path food takes inside the body

e. take what is needed

f. two Inflammatory Bowel Diseases

g. changed to a form the body can use

h. frequent and watery bowel movements

5. **diarrhea**

6. **Inflammatory Bowel Diseases**

7. **Crohn's disease and ulcerative colitis**

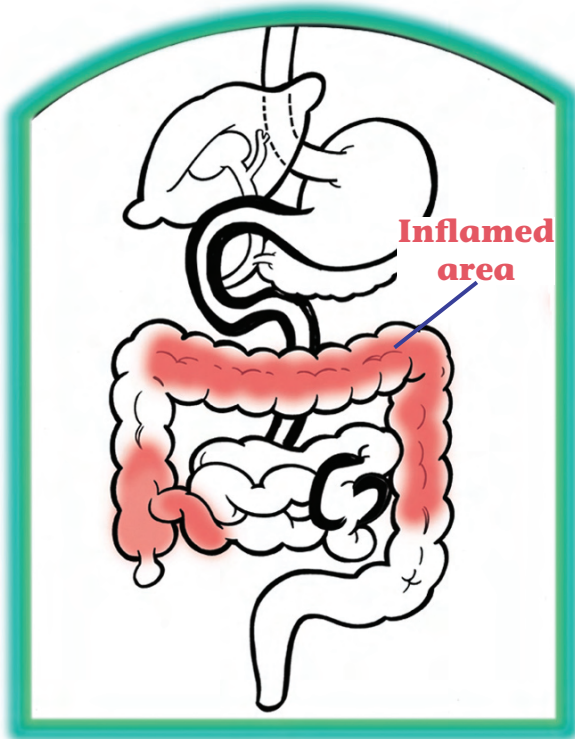
8. **digested**



# What is IBD all about?

Problems in the GI tract can be caused by an **Inflammatory Bowel Disease (IBD)**.

## The GI tract of a person with Crohn's disease



Not every person has IBD in the same place.

### Crohn's disease

**Crohn's** (krōnz) **disease** is an IBD. **Ulcerative** (ul sər ā tiv) **colitis** (kō lī tis) is another IBD. These two diseases are not exactly the same, but are very close.

When parts of the intestines get **inflamed**, or swollen, the GI tract does not work right and the body can not **absorb**, or take what it needs, from food.

The inflamed places can be spread out over the GI tract or may be all in one area.

People with an inflamed GI tract can have **diarrhea** (dī ə rē ə). These are bowel movements that are watery and happen often. They may also have pain and fever.

These problems have to be fixed so that the body can use food again to grow and be healthy.

### ulcerative colitis

**Use the GI tract above to tell which part is inflamed with IBD.**

#### Part of the GI tract

**Inflamed (swollen) or not inflamed with IBD?**

Stomach .....

Small intestine .....

Ileum .....

Large intestine .....

Rectum .....

**Tip:** Read more about IBD— it will help you understand what's happening in your body, and that makes life less scary.



# What is it Called?

Using the clues below, decide which one of the words in the box will fit in the squares below. Then use the letters in the circles to spell a word that finishes the riddle.

colitis	diarrhea	food	bowel
disease	rectum	intestinal	ileum

## CLUES

- One type of IBD is called ulcerative \_\_\_\_.
- With IBD there is often \_\_\_\_ swelling.
- The \_\_\_\_ you eat goes through your GI tract.
- The last part of the small intestine is the \_\_\_\_.
- A person with frequent watery bowel movements has \_\_\_\_.
- The end of the large intestine is the \_\_\_\_.
- Waste leaves your body in a \_\_\_\_ movement.
- One type of IBD is Crohn's \_\_\_\_.

1.

2.

3.

4.

5.

6.

7.

8.

**RIDDLE:** I feel crummy when my intestines are \_\_\_\_.

**Tip:**

Feeling sad about being sick is OK. Draw or write about it to help you feel better.



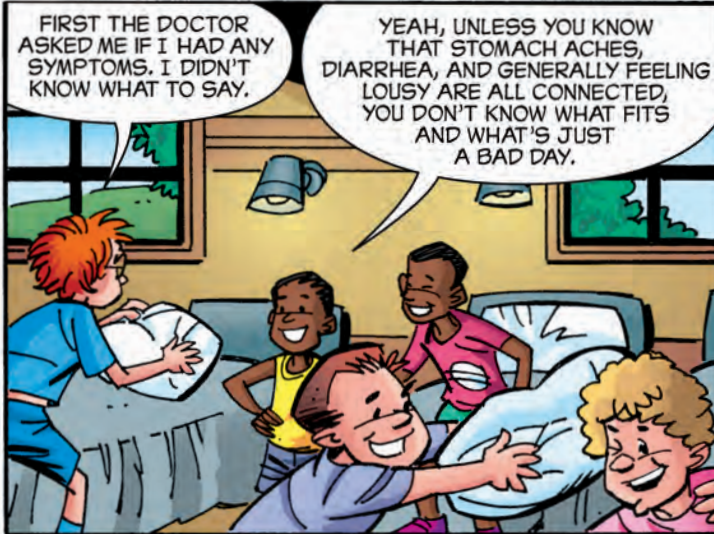
## A Slice of Life with IBD, part 2

DURING THE SUMMER, NATHAN, NAOMI, AND WALTER ATTENDED CCFA'S CAMP OASIS. EVERYONE THERE HAD IBD.



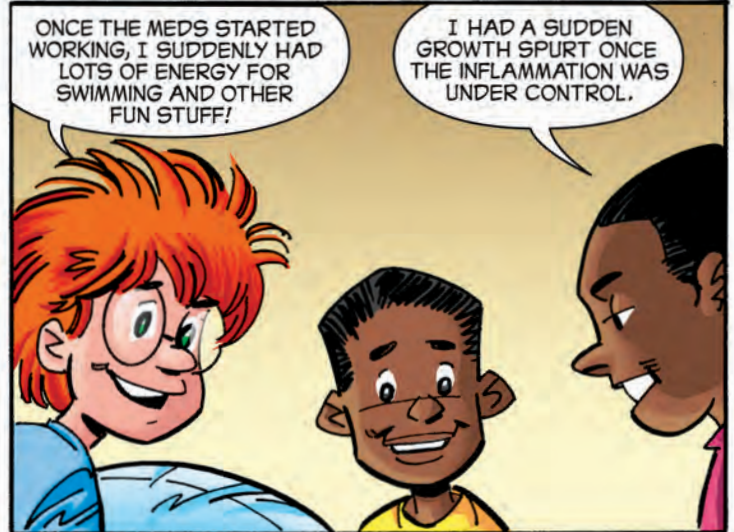
FIRST THE DOCTOR ASKED ME IF I HAD ANY SYMPTOMS. I DIDN'T KNOW WHAT TO SAY.

YEAH, UNLESS YOU KNOW THAT STOMACH ACHES, DIARRHEA, AND GENERALLY FEELING LOUSY ARE ALL CONNECTED, YOU DON'T KNOW WHAT FITS AND WHAT'S JUST A BAD DAY.



ONCE THE MEDS STARTED WORKING, I SUDDENLY HAD LOTS OF ENERGY FOR SWIMMING AND OTHER FUN STUFF!

I HAD A SUDDEN GROWTH SPURT ONCE THE INFLAMMATION WAS UNDER CONTROL.



GERMAINE WAS PLANNING TO COME, BUT HAD A FLARE.

WHAT'S A FLARE?

IT'S WHEN YOUR IBD SYMPTOMS COME BACK.



GERMAINE WAS SMART. SHE TOLD HER PARENTS AS SOON AS SHE NOTICED A PROBLEM.

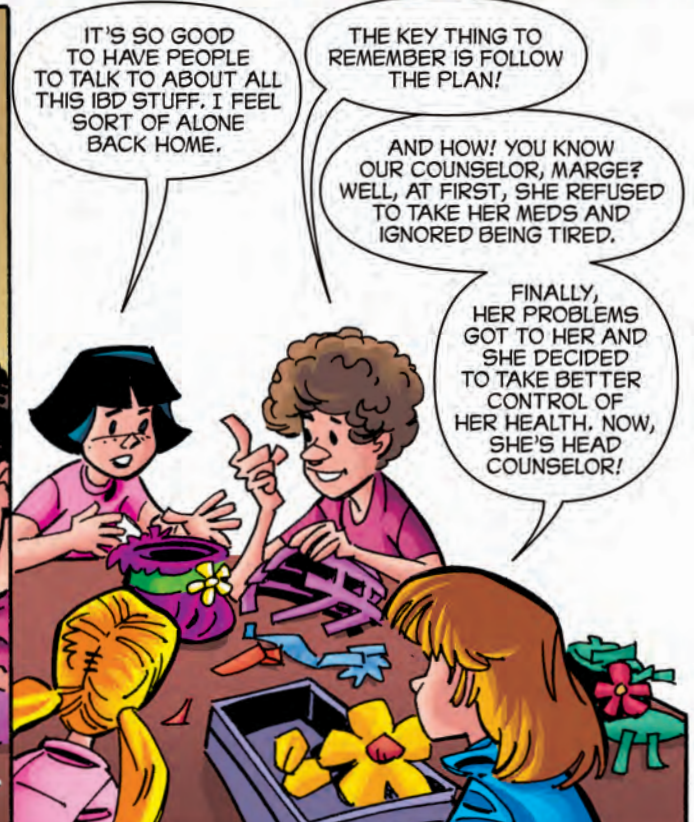


IT'S SO GOOD TO HAVE PEOPLE TO TALK TO ABOUT ALL THIS IBD STUFF. I FEEL SORT OF ALONE BACK HOME.

THE KEY THING TO REMEMBER IS FOLLOW THE PLAN!

AND HOW! YOU KNOW OUR COUNSELOR, MARGE? WELL, AT FIRST, SHE REFUSED TO TAKE HER MEDS AND IGNORED BEING TIRED.

FINALLY, HER PROBLEMS GOT TO HER AND SHE DECIDED TO TAKE BETTER CONTROL OF HER HEALTH. NOW, SHE'S HEAD COUNSELOR!





# My Healthcare Team

You have a healthcare team. It includes members of your family. It might have one or two doctors and a nurse or two. Sometimes, a team will have a social worker or a dietician. Your healthcare team wants to keep you strong. They want to keep your symptoms under control.

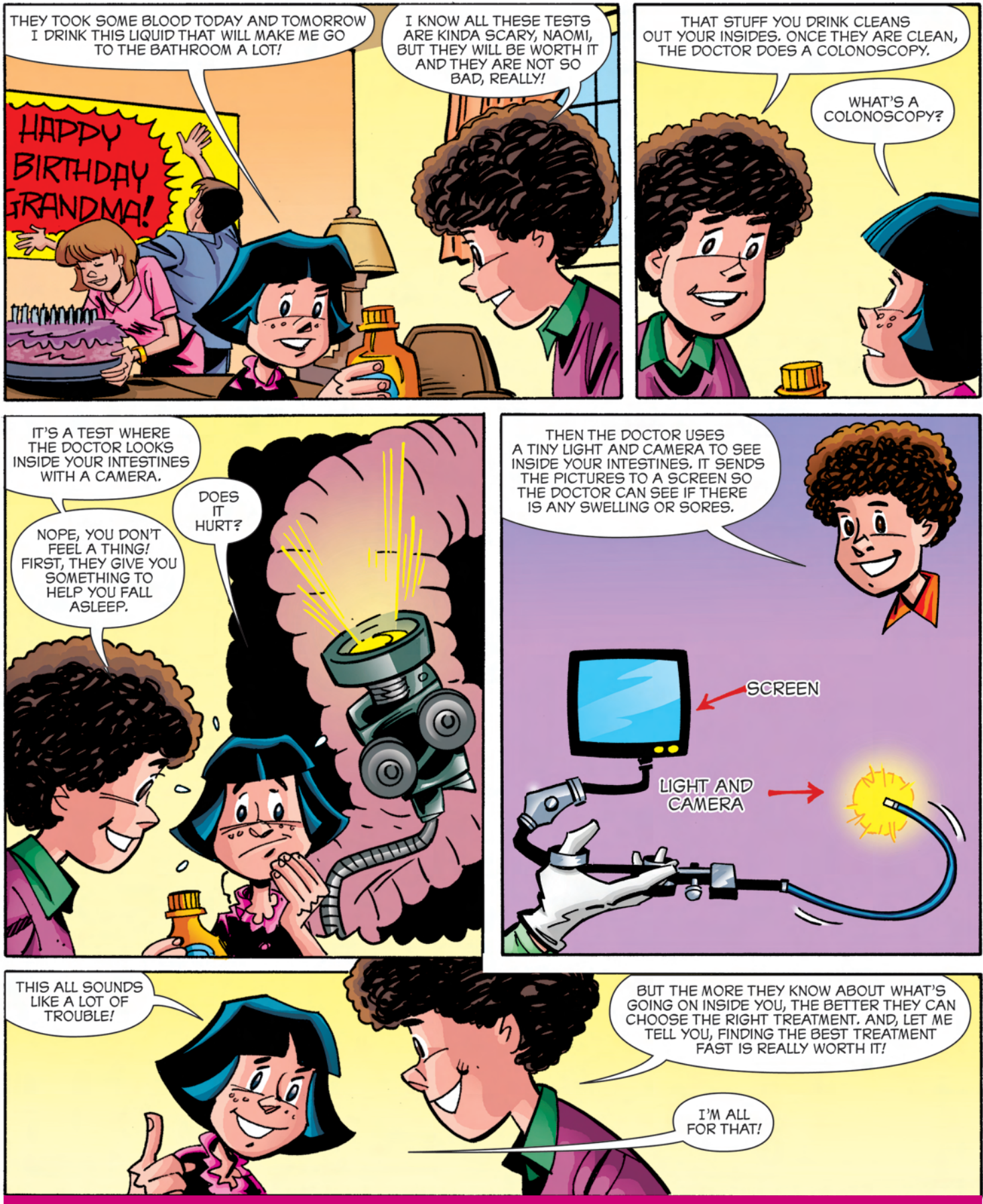
**Fill in the names of your own healthcare team.  
Then write or draw how each one helps you.**

A picture of Me!

My name

**Tip:** Be honest with your healthcare team. Their goal is to help you!

## A Slice of Life with IBD, part 3



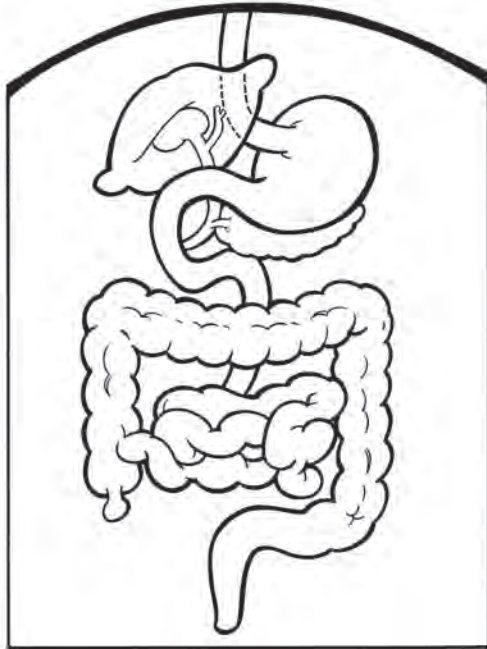


# My Diagnosis

**Talk to your doctor. Then finish each sentence with words or a picture to tell about your diagnosis and how you feel about it.**

The type of IBD I have is \_\_\_\_\_

The inflammation is in the \_\_\_\_\_ area of my GI tract.



**Color where the doctor found the inflammation in your GI tract.**

The doctor says to deal with my IBD I must:

---

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The doctor said I will need to pay attention to my illness by watching for certain changes. *Red flags* will be the code words for these changes. I need to tell someone immediately when these *red flag* changes happen.

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*My Red Flags*

**Tip:** Know your "red flags" and tell someone when they happen!

# What About Medicine?

- There are 5 classes of medicines used to treat the symptoms of Crohn's disease and ulcerative colitis.
- Some of the medicines are used to treat the symptoms of both diseases.
- No medicine has been invented that cures IBD.
- The medicines can be pills, liquids, intravenous (put directly into the blood), and suppository (through your rear).
- The medicines help you go into remission (ri mi shən). This is when your symptoms disappear for a period of time.
- Check with your doctor or ask your parents more about your medicine.

## Aminosalicylates

(a mē nō sal ə sī lāts)

- Reduces inflammation
- Prevents flares

## Antibiotics

(an ti bī ōt iks)

- Reduces the bacteria in the GI tract to control symptoms, like diarrhea
- Usually used for a short time

## Biologic Therapies

(bī ō log ik ther ə pēs)

- Used for maintaining remission
- Usually used after other medicines have been tried

## Corticosteroids

(kor tə kō stār oids)

- Reduces inflammation
- Used to treat flares

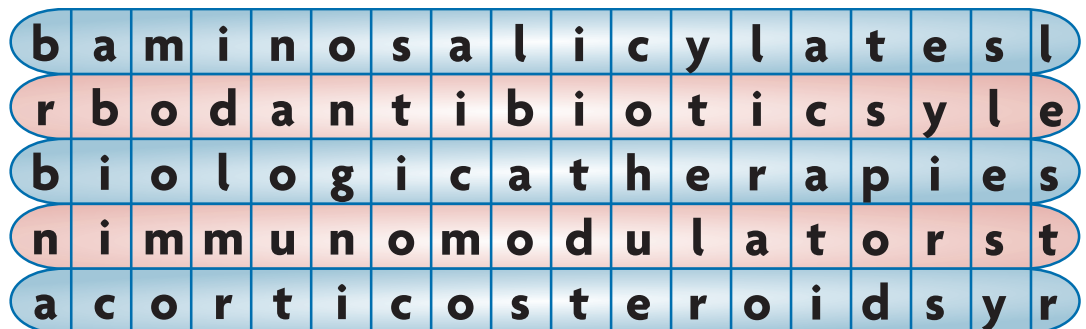
## Immunomodulators

(im ū nō mod ū lā tors)

- Stops inflammation
- Used to help maintain remission

## WORD FIND

Each line contains the name of one of these classes of medications. Can you find them?



**Tip:** Problems taking pills? Check with your doctor. Ask if they can be cut, crushed, or be taken with something slippery to help them slide down.











# Bathroom Tracker

Germaine's mother kept embarrassing her with questions about what went on in the bathroom. Germaine and her mother created a Bathroom Tracker, so her mother would stop asking so many questions. They decided to use color coding, so no else knows the details. Germaine used a crayon to mark the tracker each time she went to the bathroom. You and your folks can come up with your own tracker or use the one below.

## Germaine's Bathroom Tracker

**WEEK** OCT 4 - 10

<b>SUNDAY</b> <i>Time of Day</i>	<b>I HAD:</b>
8:30	
1:00	
3:30	
7:15	

<b>THURSDAY</b> <i>Time of Day</i>	<b>I HAD:</b>
8:00	
11:40	
3:50	
8:30	

Blue = normal b.m

Yellow = just gas

Red = bloody b.m.

Green = diarrhea

Purple = other

## My Bathroom Tracker

[illegible]

**Tip:** *If your rectum's sore, use a moist wipe instead of toilet paper.*

## Code Words

Some topics are difficult to talk about, but you have to. Parents often ask about what happened in the bathroom, and how you feel, and they want you to describe these things in detail, sometimes in front of other people!

### Using code

One way to get around this problem is to talk in code. You can make your own code words. For example, use the word *bottom* instead of *rectum*. Encourage the people you know to use these code words with you. Explain to them that it will be easier for you to talk about your IBD if they use code.

**Here are some ideas. Add your own code words to this list!**

Words or Ideas	Code Words
diarrhea	runs, goop,
rectum, anus	bottom, butt, down there,
pain in the gut	pang, twitch, cramp,
nauseous	queasy, unsettled, sick,
bowel movement	b.m., a drop,
vomiting	hurling, tossing cookies,
bathroom	throne room, other place, second home, john,

**Can you break this code? Figure out the coded sentences below.**

**HINT:** Start at the letter given and count three down the alphabet. Write that letter in the blank below. (If you see an **f**, count three letters and write an **i** in the blank.)

Q	e	f	p	f	p	x	m	x	f	k	f	k	q	e	b	y	r	q	q

F	t	l	r	i	a	o	x	q	e	b	o	y	b	m	i	x	v	f	k	d	q	e	x	k
p	f	q	q	f	k	d	l	k	q	e	b	q	l	f	i	b	q							

**Tip:** Parents can embarrass you without realizing it, but remember— it's just because they care!



# Life With IBD

It's a journey!

**START**

## How to Play

On the inside back cover, cut out the player pieces and the number card. Fold up the sides on the number card and tape the corners together to make an open box. Find a small coin, stone, or button to toss into the box to determine how many spaces to move.

The goal of the game is to become an **IBD HERO** by remaining in remission!

Players each choose a piece and put it near **START**.

The youngest player begins the game by tossing the coin into the number box. That player

moves the number of spaces shown. If the coin lands on more than one number space, use the number on which most of coin lands. The player moves their piece that number of spaces, reads aloud what it says on that space, and follows the directions. The player moves ahead or back, and remains on the new space.

Then the next player (moving clockwise) tosses the coin and moves accordingly.

The first player to reach the end becomes the first **IBD HERO** and gets to perform a victory dance.

The game continues until each player has become an **IBD HERO**, too.

**BAD STOMACH CRAMPS**  
BACK 1 SPACE

**CONTINUAL DIARRHEA**  
BACK 2 SPACES

**VISIT TO DOCTOR**  
AHEAD 1 SPACE

**VISIT TO GI DOCTOR**  
AHEAD 2 SPACES

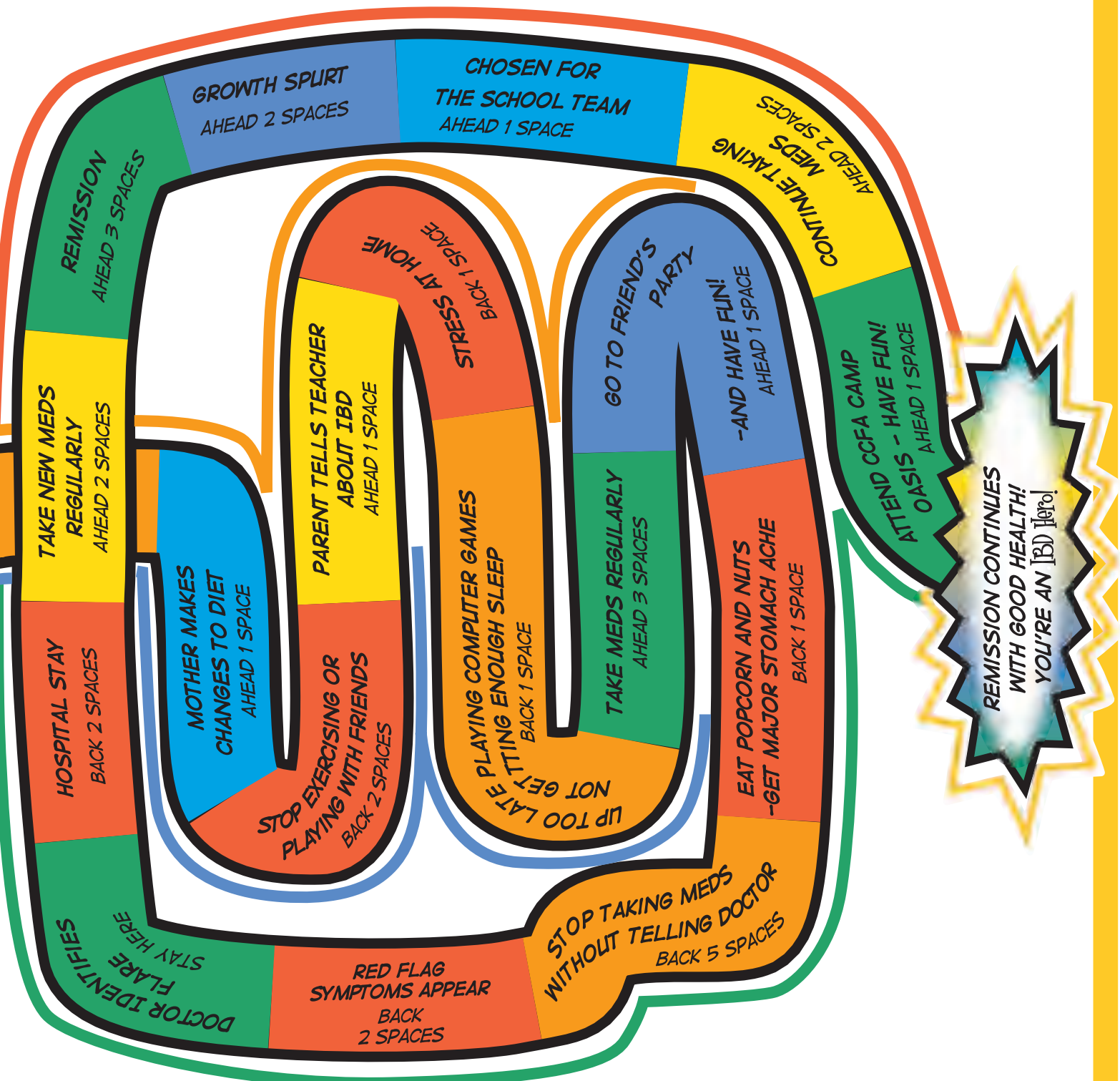
**COLONOSCOPY**  
AHEAD 1 SPACE

**BLOOD TEST**  
AHEAD 2 SPACES

**DOCTOR DIAGNOSES IBD**  
STAY HERE

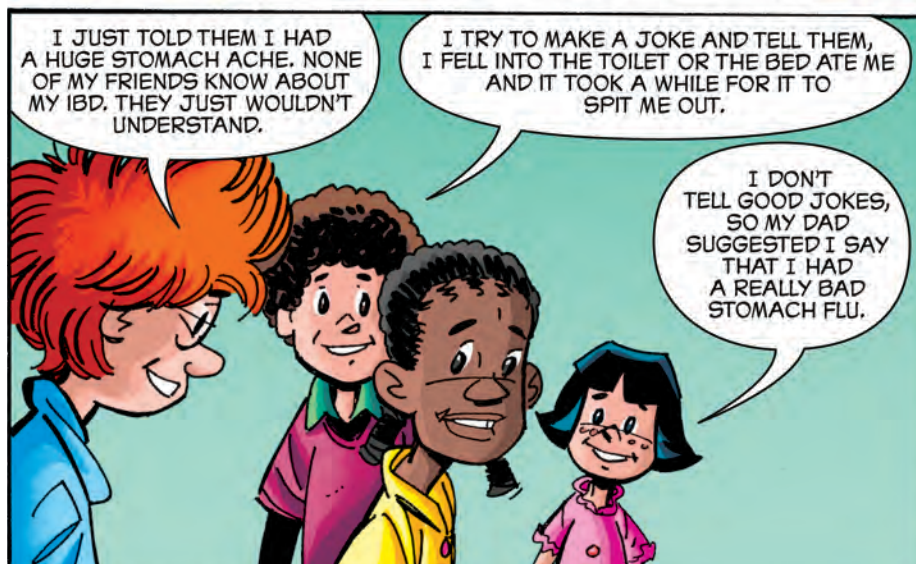
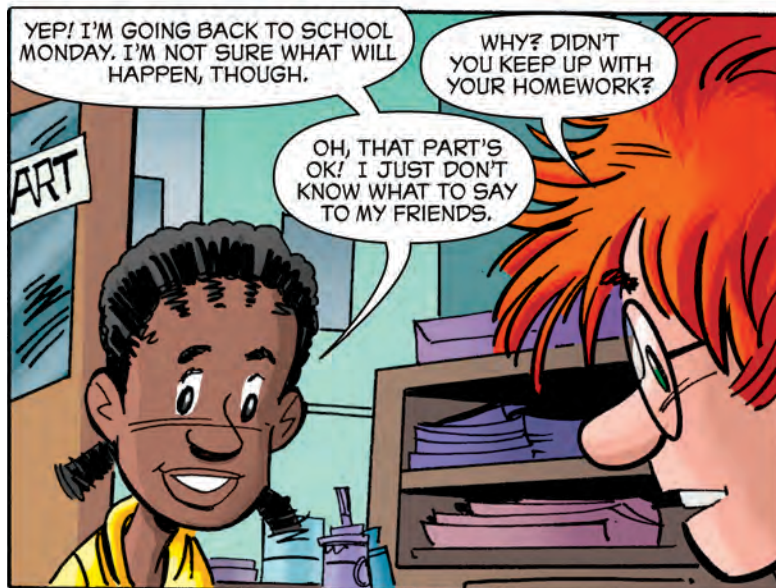
**DOCTOR PRESCRIBES MEDICINE**  
AHEAD 2 SPACES

**FORGET TO TAKE MEDICINE**  
BACK 1 SPACE





# A Slice of Life with IBD, part 4





## Sharing Feelings

Sometimes we hide how we feel. We smile when we are feeling sad or sit quietly when someone says something that hurts our feelings. That's okay. This is a way to get through a hard time.

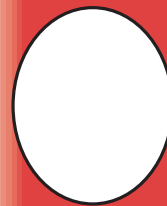
**Read each of these short stories. Then draw a face to show what your face would look like to others, and next to it, how you feel inside. You might draw a sad face for what people will see, but a scared face to show what you are feeling.**

**W**hile at the mall, you rush to the bathroom and realize you're having some of your problem symptoms. Then you search all the stores to find your mother to tell her what you've found.

My face shows  
people I'm

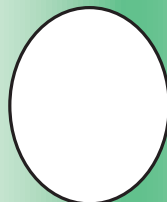


But I'm  
feeling  
upset

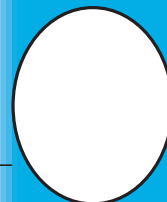


**O**ne of your friends just yelled across the baseball field to ask why you are leaving to go to the bathroom during the game.

My face shows  
people I'm



But I'm  
feeling



**Now think about how others treat you and what they say to and about you. Finish each of these sentences with a picture or words.**

I wish the people who know about my IBD would \_\_\_\_\_

I would be more comfortable if my friends would \_\_\_\_\_

My family sometimes embarrasses me when \_\_\_\_\_

**Tip:** Remember, some people just don't understand you and your IBD.



## Max's Friends

**M**ax has IBD. He has not told any of his friends. Paul is a good friend, but he teases Max about spending so much time in the bathroom. Don is another friend. He just stares at Max when he gets

back from the bathroom. Wendy calls him "Bathroom Boy."

Max talks to Ms. Klein at the doctor's office. She helps him make a list of things he can tell his friends.

**This is Max's list. Add your own ideas to it.**

WHEN THEY ASK:

I CAN SAY:

What's wrong with you?

-It's a stomach thing.  
-The part of my body that digests food gets swollen sometimes.

Can I catch it?

-Don't worry, you can't catch it!

Are you OK?

-I'm gonna be fine; it just comes and goes.

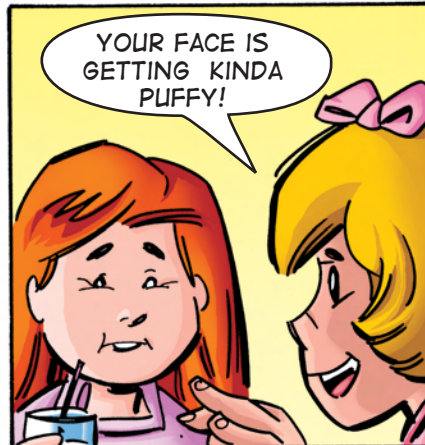
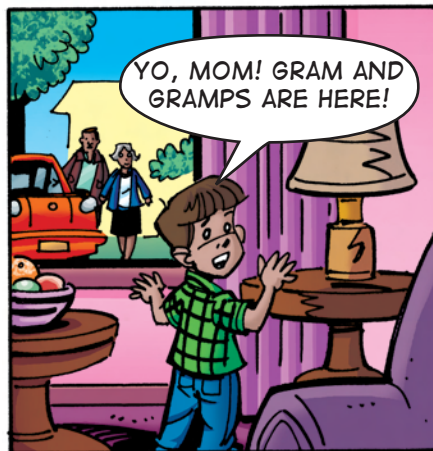
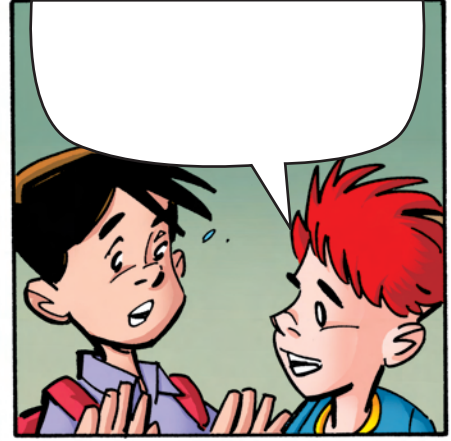
Why is your face so puffy?

-It's because of my medicine.  
-I must be eating a lot at home to make up for the bad cafeteria food.  
-I wish it could have been from eating a lot of candy!

**Tip:** Walk away when you don't want to say any more.

## What To Say

Look at each story. Think about what a person with IBD might say. Write what you would say in the balloon to finish the story.



**Tip:** Remember, it's your choice on how much to tell someone outside your health team.



## If it were me...

We have to make choices every day. Sometimes we can plan ahead, and sometimes we have to go with the flow. In these stories, each person has to make a choice. None of them are wrong, but some people may feel happier about making one decision than another.

**Read each story. Which choice or choices would YOU feel most comfortable with? Add another choice if you have another idea.**

**Naomi's** dance class was going to practice at a theater. In six weeks they had to dance in a performance there. Naomi was afraid she'd have problems with her IBD while in the theater. What would YOU choose to do?



- With your parent, check out where all the bathrooms are in the theater.
- Explain the situation to the dance teacher. Ask for extra bathroom time.
- Once you get to the theater, sneak away to find the closest bathroom.
- \_\_\_\_\_

**NATHAN'S** Little League team won the town championship. His team is going out to celebrate. What would YOU choose to do?



- Join the team. Eat anything you want, but know where the bathroom is.
- Join the team, but locate the bathroom as soon as you get there, and be a picky eater.
- Don't go with the team, but celebrate with your family at a familiar restaurant.
- \_\_\_\_\_

**Walter** loves to play video games. He and his friend George want to spend Saturday afternoon playing them. George does not know about Walter's IBD. What would YOU choose to do?



- Tell George about the IBD.
- Tell George you have a stomach ache and have him come to your house. Disappear into the bathroom when you need to.
- Go to George's house, but find the bathroom before you settle down to play. Disappear into the bathroom when you need to.
- \_\_\_\_\_

**Tip:** Bring your own food and bring extras for your friends!

# Knotted up over IBD Symptoms!

Nathan's IBD had not bothered him for several years. One day, his IBD symptoms began reappearing. He decided to take care of himself. Nathan listened to his doctor and took some new medicine. He could no longer play baseball, so he watched games on TV and followed his favorite players on the Internet. After a while, his new medicine worked. He could do more things, but he was still weak. Finally, he got back to his everyday life of school, Little League, friends, and computer games.

**Below, each gray box has a problem related to how or why your IBD symptoms might bother you. It can be traced to a box on the bottom of the page, where a good way to solve the problem is listed.**

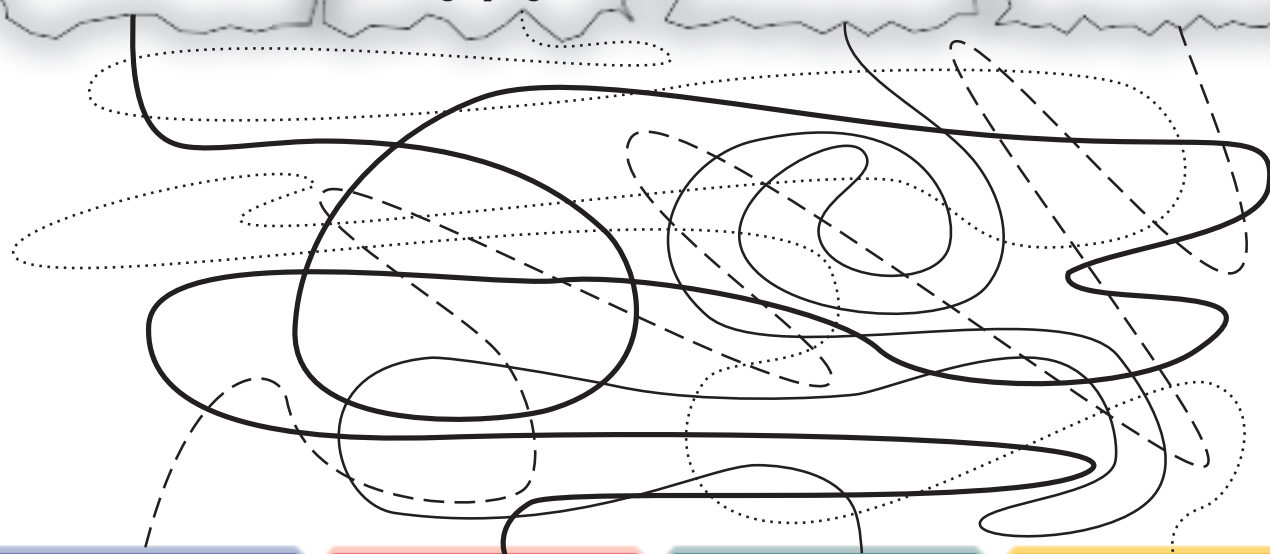
**See if you can follow the path of each piece of string from the problem to the solution. Use a different color to trace each piece.**

**1.** You ate a meal of fried chicken nuggets and fries. Then your IBD red flag symptoms began.

**2.** You are on a school field trip and get diarrhea. This is one of your clues that your IBD is starting up again.

**3.** Your IBD symptoms have lasted many days. It has made you very tired.

**4.** You didn't take your medicine regularly, so now your IBD is giving you problems.



Be sure to take your medicine according to your doctor's orders. Doing this may save you from IBD symptoms.

Watch to see what foods cause a problem for you. Stay away from them to save yourself the problems of IBD.

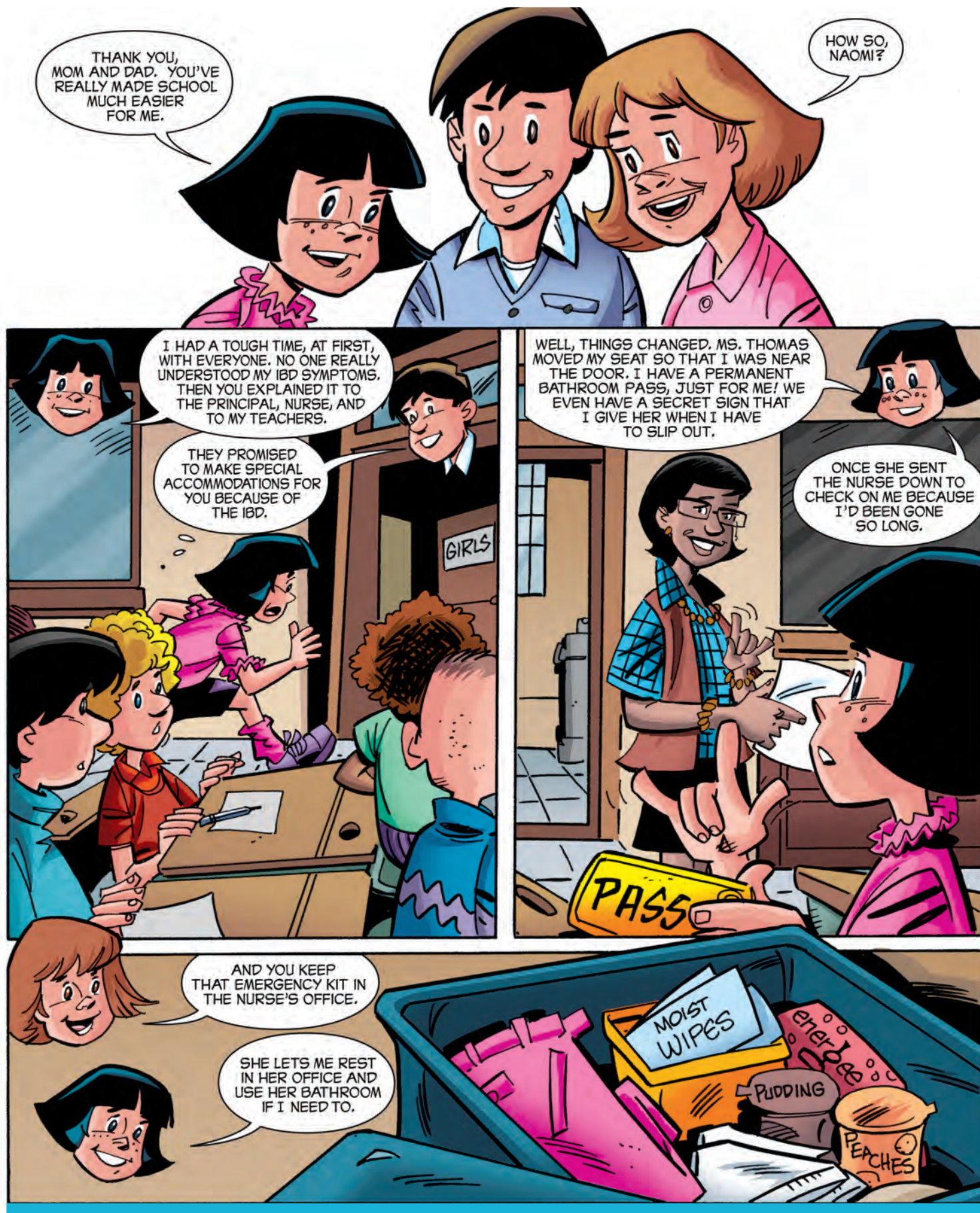
Do quiet activities until you get your strength back. Text your friends. Read sports magazines instead of playing sports.

Have an emergency kit with you. Include underwear, pants, wipes, and deodorizer.

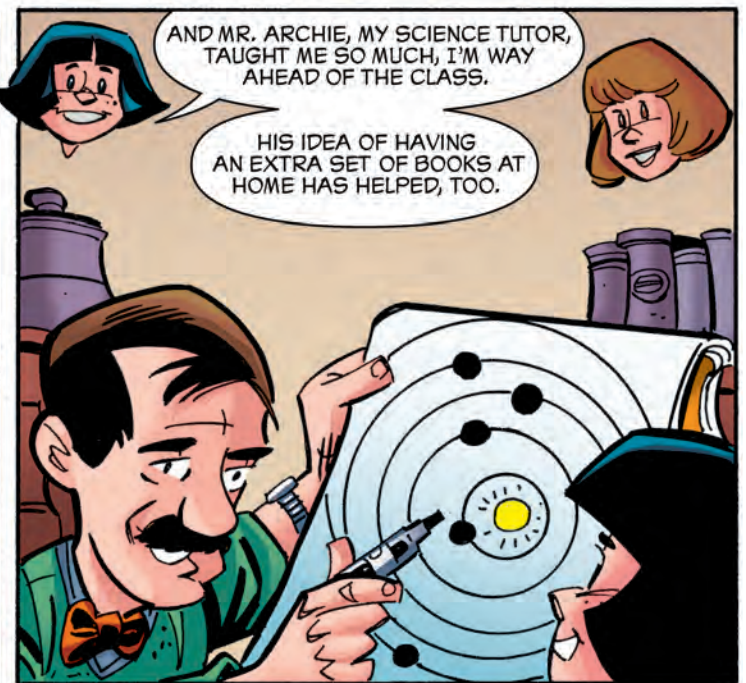
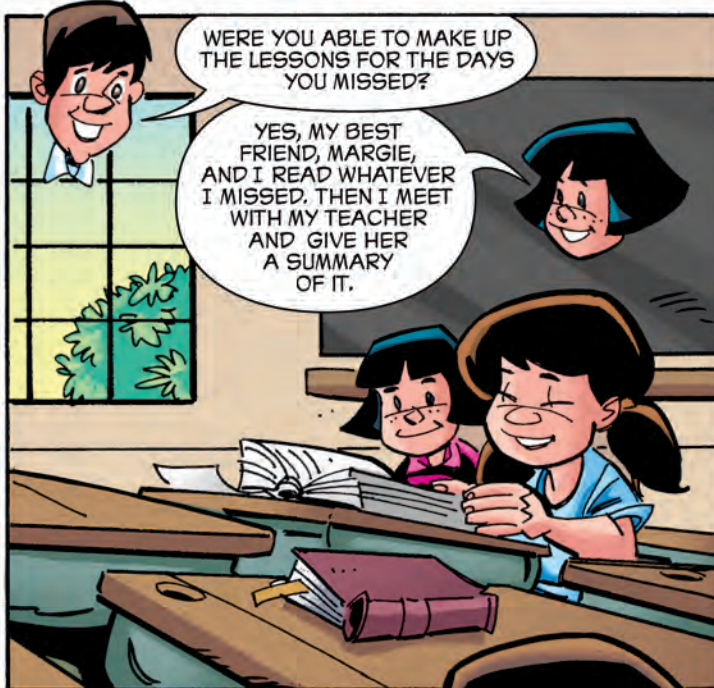
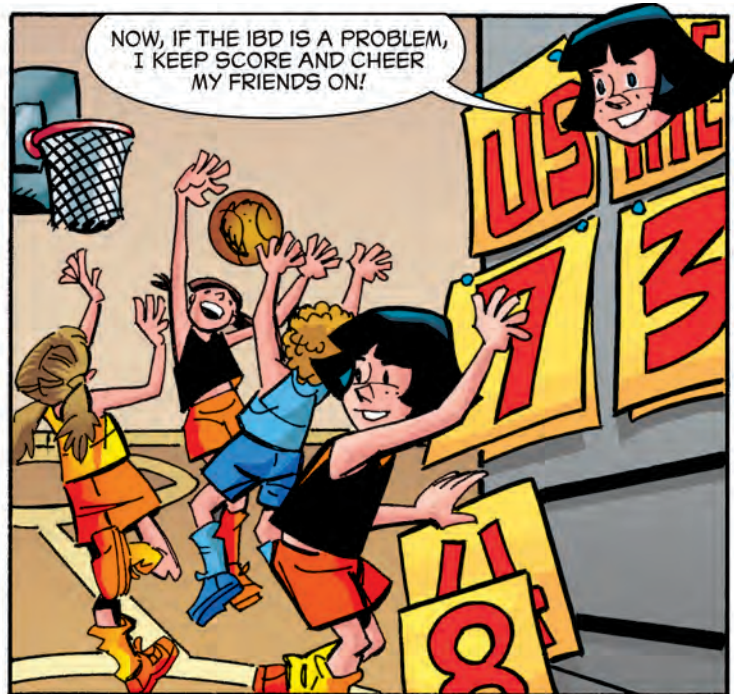
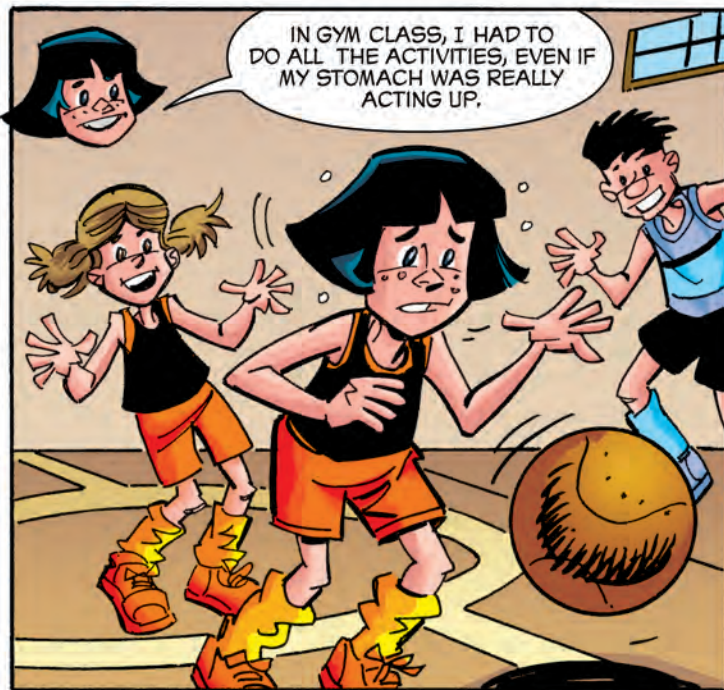
**Tip:** *IBD can have ups-and-downs, so control what you can!*



# A Slice of Life with IBD, part 5









# Away From Home

Dear Diary,

Traveling is hard with IBD. But I am having fun on this trip!

At the airport I had to find the bathroom fast. There were so many signs that it took me a while to figure out which way to go. I finally found a bathroom, but it had a line. I JUST made it!

On the plane, we had seats near the bathroom. I watched the light to make sure no one was in it. I was VERY glad it was a short flight.

On the drive to the hotel we stopped at a gas station. It had two bathrooms and I had to get a key to get in. It was gross! I wouldn't have used it if I didn't have to!

At dinner, I stood looking at the restrooms signs. I wasn't sure which one to use. Sometimes the signs can be confusing!! Thank goodness they had pictures on the door.

We went to the beach and sat in the sand near the bathrooms, so I didn't have to worry. We had a great time!

I have seen LOTS of bathrooms, and I found out that if I have a plan, I don't have to worry!

**Match the sign to the person who can use the restroom.**

**GALS**



*Lassies*



**Señor**



**Señoritas**



*Lads*

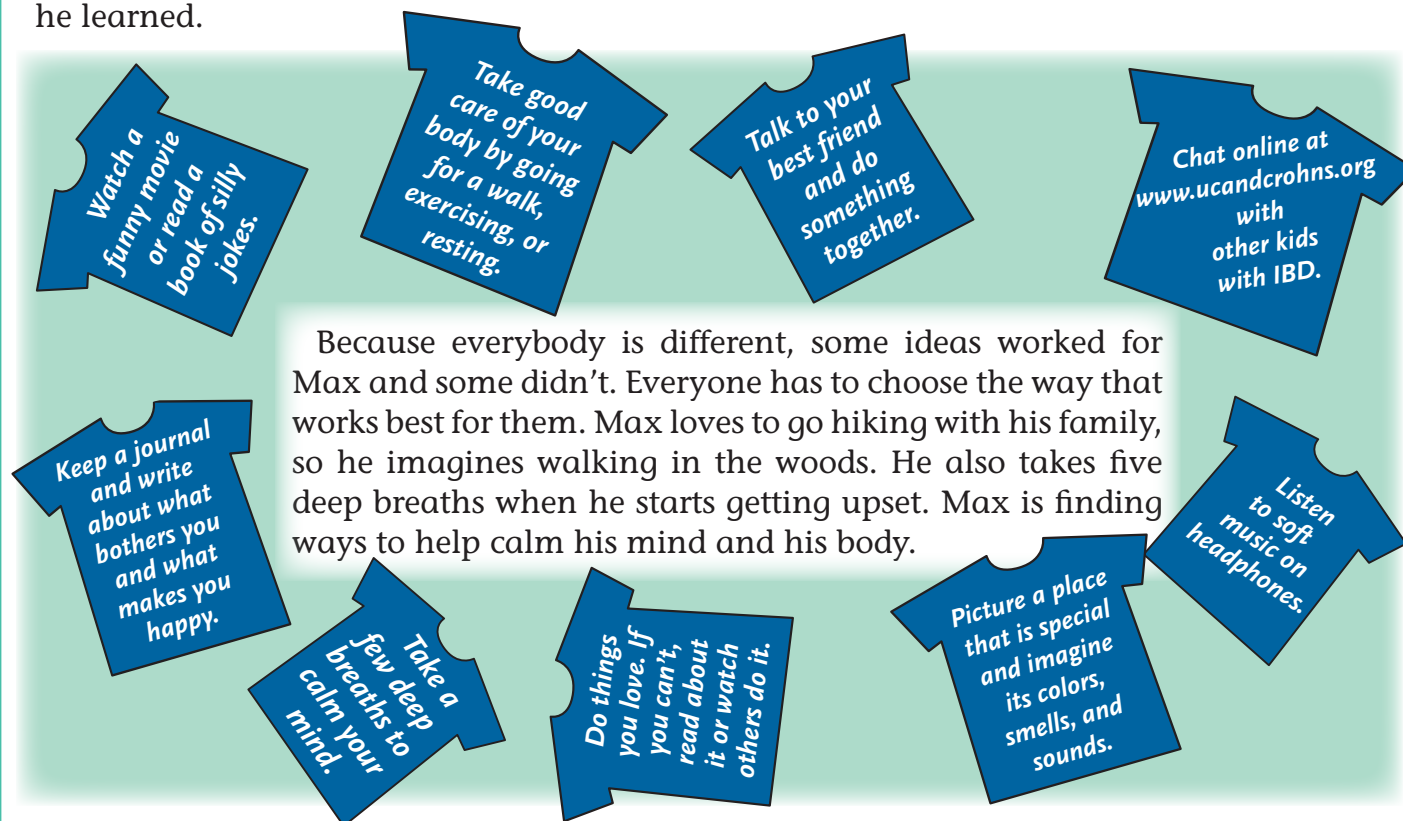
**GUYS**

**Tip:** If a sign says "No public bathroom," ask anyway. Use an "I Can't Wait" card from CCFA. If you explain, people often say yes.

# Living with Challenges

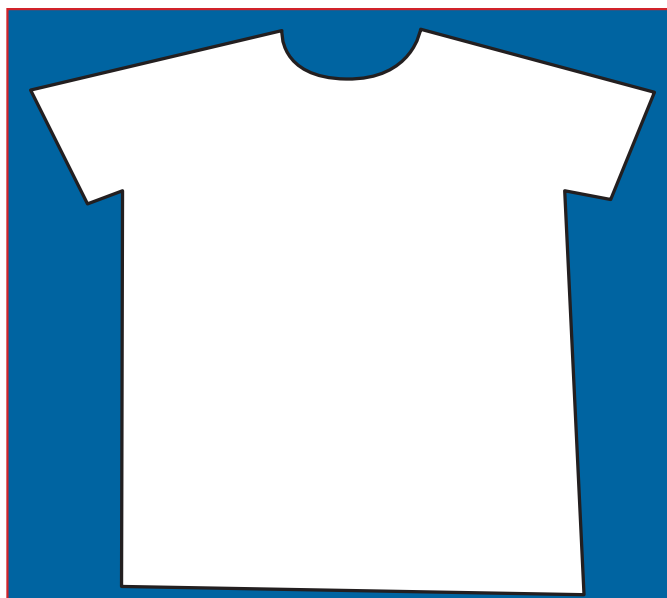
"Just leave me alone!" yelled Max. School is starting next week and he is worried about school, his friends, and his IBD. His IBD is giving him problems. For some people, like Max, their bodies react when they get stressed out. So today, this is making his IBD worse.

Max talked to a social worker about controlling his worrying to help calm his IBD. She helped Max find ways to calm his mind when it affects his body. Here are some of the things he learned.



Because everybody is different, some ideas worked for Max and some didn't. Everyone has to choose the way that works best for them. Max loves to go hiking with his family, so he imagines walking in the woods. He also takes five deep breaths when he starts getting upset. Max is finding ways to help calm his mind and his body.

**Choose the ways that work best for you. Decorate this t-shirt with those things and activities that make you feel good and could help you calm your mind. Think about them when you begin to get upset.**



**Tip:** Get rid of the things that are bothering you by writing or drawing them. Throw away the paper after you are done.



# IBD Heroes Do What They Love



## Sarah Lang

World Champion Speed Skater

*"I was hospitalized with horrible gastrointestinal pain before being diagnosed with ulcerative colitis," says Sarah Lang, who was training for the World Cup at the time. "I didn't think I'd be able to skate again after being diagnosed but then had the best results of my career. You can achieve anything — even if you didn't think it was possible before."*



## David Garrard

NFL Quarterback

*"After being diagnosed with Crohn's disease in 2004, I was able to get back on the football field," says David Garrard, NFL quarterback. "I didn't let inflammatory bowel diseases take over my life and you can beat this too. You can defeat anything!"*



## Scott Speed

NASCAR Driver

*"Going 200 miles an hour in my race car, I can't let my ulcerative colitis get in the way," says Scott Speed, NASCAR driver. "I don't let my ulcerative colitis stop me from winning and I encourage you to not let IBD stop you from winning too."*



## Heath Slocum

PGA Tour Champion

*"I was sidelined from playing professional golf when I first got sick with ulcerative colitis," says Heath Slocum. "I really wanted to get back on the course and play golf, and with help from my doctors and family, I was able to start playing again. I won three PGA Tour tournaments and have represented the USA in the World Cup since. No matter what you want to do — you can be a champion too!"*

## Answers

### PAGE 2 - MATCHING

1.d, 2.c, 3.a, 4.e, 5.h, 6.b, 7.f, 8.g

### PAGE 3 - GI TRACT

Stomach: *not inflamed*, Small intestine: *not inflamed*, Ileum: *inflamed*, Large intestine: *inflamed*, Rectum: *not inflamed*

### PAGE 4: - WHAT IS IT CALLED?

1. colitis, 2. intestinal, 3. food, 4. ileum, 5. diarrhea, 6. rectum, 7. bowel, 8. disease. Riddle: I feel crummy when my intestines are inflamed.

### PAGE 9 - WORD FIND

b a m i n o s a l i c y l a t e s l  
r b o d a n t i b i o t i c s y l e  
b i o l o g i c a t h e r a p i e s  
n i m m u n o m o d u l a t o r s t  
a c o r t i c o s t e r o i d s y r

### PAGE 11 - BREAK THE CODE

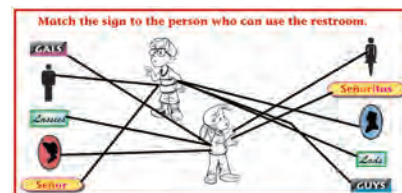
FIRST CODE: This is a pain in the butt.

SECOND CODE: I would rather be playing than sitting on the toilet.

### PAGE 19 - FOLLOW THE PATH

1.- red box 2.- yellow 3.- green 4.- blue

### PAGE 22 - MATCH THE SIGNS



## Now that you know what IBD is, you need to know some other really important things:

- \* **Nothing you ate or did gave you IBD.**
- \* **You didn't catch it from anyone else.**
- \* **Most people who live with IBD are healthy more often than they are sick.**
- \* **Kids with IBD can be whatever they want to be and do whatever anyone else can do: go to school, date, go to college, have a career, get married, have kids, travel, be a hero — *you name it!***

You'll have a ton of questions about your illness, many now and many more as time goes on. That's okay.

You'll be doing yourself a big favor if you learn everything you can about your IBD and how it affects your body. Just ask! One place to learn more is:

**[www.ccfa.org](http://www.ccfa.org)**



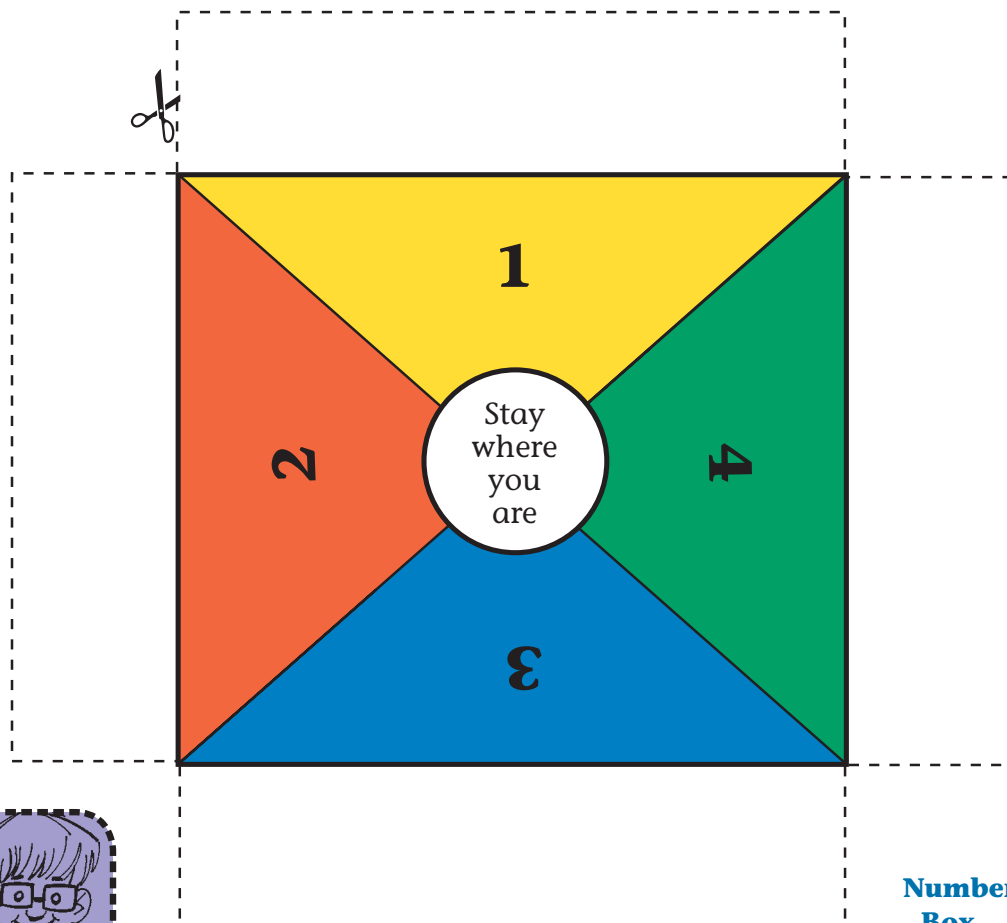
These are the number box and playing pieces to use with the game board on pages 12-13.

Cut out one playing piece for each player. Cut out the number board on the dotted line. Fold the white sides up and tape the board at the corners. This will make an

open box into which you can toss a small coin, button or stone.



**Player Pieces**



**Number Box**





## Improving Quality of Life

We know living with Crohn's or colitis can have its ups and downs, but you are not alone.

***We are here to help.***

### INFORMATION AND SUPPORT

Toll-Free Phone Number	888.MY.GUT.PAIN (888.694.8872)
E-mail	info@ccfa.org
Web site	www.ccfa.org
Teen web site	www.ucandcrohns.org
Camp Oasis	www.ccfa.org/kidsteens/camp
Take Steps program	www.cctakesteps.org

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