

THE TRANSFER TOOLKIT

by the transition
task force
of
 IMPROVE**CARE**NOW™

A GUIDE FOR YOUNG PEOPLE WITH IBD,
THEIR FAMILIES, AND THEIR CARE TEAMS

with tools and stories
to ease the transfer to adult care



THE TRANSFER TOOLKIT

SKILLS TO GAIN BEFORE YOU GO

It was a little scary at first, but the more and more I went to visits on my own, the more prepared I felt to be seen by an adult provider. Over time you become a pro, and you really grow as a person with each new challenge.

- Randa



DO I KNOW ... ?



- The name and location of my disease?
- The tests, procedures, and surgeries I've had?
- The names and doses of my medications?
- What medications did not work for me?
- What can make my symptoms worse?
- My insurance coverage and its limitations?



DO I UNDERSTAND ... ?

- What to do if I experience symptoms?
- The possible side effects of my medications?
- What medications or other substances I can't have and why?
- The risks of not taking my medications or not going to appointments?

Some pediatric doctors require that their patients transfer care when they reach a certain time (e.g. age 18 or 22). Know when you may be expected to transfer your care.



AM I ABLE TO ... ?

- Identify reputable sources of information about IBD?
- Find out if a medication or test is covered by my insurance?
- Make appointments, refill medications, and ask questions between visits?
- Prepare for and speak for myself at my appointments?
- Ask for help when I need it?

My pediatric doc was moving to another hospital, so I had to move when he moved, a year prior to when I would have moved at age 20. Be willing to embrace the change and also be ready to advocate for your needs. - Alex





WILL THIS TEAM MEET MY NEEDS?

Will I see the same doctor every time?

Does this care team specialize in IBD?

Will I have access to a multispecialty care team, including a surgeon, psychologist, dietitian, and/or social worker?

Is an anesthesiologist available for procedural sedation?

Is there a dedicated advocate for IBD patients?

HOW CAN I COMMUNICATE WITH MY IBD TEAM?

What is the preferred method
of inter-visit communication?

Is there a single point of contact?

When can I expect a response?

Is after-hours help available?



I chose a female GI to be my doctor, as I had only had my male pediatric GI and was unsure of how I would feel with a male provider as I continued to go through puberty. - Jennie



WILL THE CARE I RECEIVE BE CONVENIENT FOR ME?

How quickly can I be fit into the schedule for an urgent need?

Where would I have visits, get infusions, be scoped, be hospitalized, or have surgeries?

Does my insurance cover all specialities within my care team?

Will I get charged if I need to cancel an appointment?

WILL I RECEIVE THE RIGHT CARE FOR ME?

Is the team actively involved in IBD organizations and research?

How long are appointments, and how much time will I be with my doctor?

Do I know anyone else who visits this team? What is their perception?



1. REVIEW YOUR RECORDS BEFORE YOUR FIRST APPOINTMENT.

Jog your memory and be sure to check for accuracy! Ideally, your pediatric team will have written a summary of you and your IBD for your new care team to review.

2. TELL YOUR CARE TEAM EVERYTHING YOU CAN ABOUT YOURSELF, WHAT YOU DO, AND HOW YOU FEEL.

The more information the doctor has, the more helpful they can be.

3. BRING A LIST OF QUESTIONS AND CONCERNS.

You can keep a running list on your phone or computer in between visits.

4. ASK QUESTIONS.

When it comes to your health, any question on your mind is a valid one. If you don't understand an answer, ask the doctor to explain it again until you do understand it.

If you don't seem to be clicking with your doctor, it is 100% valid to switch. In fact, I would recommend consulting with another doctor whenever you have any concerns about your medical treatment, even if it is minor. A good doc will encourage outside opinions. - Grady



5. WRITE DOWN WHAT YOUR CARE TEAM SAYS.

Given the wide scope of many visits, notes can help you recall the discussion later.

6. BE ASSERTIVE. BE NICE. BE PERSISTENT.

You know your body best. It is okay to respectfully disagree with your IBD team or to offer a different opinion. Consider bringing a friend or family member as a "confidence buddy" to support you or provide another perspective.

7. PRACTICE ESSENTIAL SKILLS.

Try refilling medications yourself (before they're empty), being the first to talk at an appointment, or giving your medical history to a family member or friend to practice.

To know what your insurance will cover, where they'll cover, and what you'll owe, check your insurance card for the best website to visit or number to call. If your insurance denies a treatment, ask your IBD team for help.

Here's a short primer on some of the most commonly used health insurance terminology in the United States. Best to check with your insurance provider to determine their exact definitions.

IN-NETWORK

Some insurances will only cover care received by "in-network" hospitals or doctors. If traveling, be sure to check with your insurance company a long time beforehand.

DEDUCTIBLE

The amount of money you have to pay for your healthcare yearly before your insurance "kicks in."

COINSURANCE

Once your insurance "kicks in," this is the cost of your care "left over" after insurance pays its part. This is usually a pre-set percentage, not a flat amount (i.e., your insurance pays 80% of Service X, and you pay 20% of Service X, each time it is received.)



Since I'm on my parents' insurance, I co-manage my insurance with my mom. I pay the bills, and communicate with my care team and the pharmacy. Meanwhile, she helps me navigate our health plan and any appeals we need to make. - Sami

COPAY

Different than coinsurance, this is a pre-set flat fee associated with a particular type of healthcare encounter. For example, your insurance may require you to pay a certain amount of money on-the-spot every time you visit your IBD doctor's office.

OUT-OF-POCKET LIMIT

Most plans set a dollar amount that is the maximum you should have to pay in one year, including deductibles, coinsurance, and copays.

HAVE MEDICAID?

For most young adults, their "child" Medicaid discontinues at age 18/19. Applying for "adult" Medicaid is an option, but there is variation across state Medicaid programs that influences coverage. Applying for "adult" Medicaid prior to losing "child" Medicaid is very important.

Another option for coverage is the Affordable Care Act. This is a federal program that provides options for private insurance coverage, so please explore this option prior to losing Medicaid.

You may need other care, too! Talk to your team, and follow the latest recommendations from the Crohn's + Colitis Foundation.



OTHER SPECIALISTS YOU SHOULD VISIT

SKIN CANCER SURVEILLANCE

The use of certain IBD medications may increase the risk of skin cancer. Getting a yearly skin check, even if you don't see any changes, is important.

SEXUAL HEALTH

Discuss with your doctor how your medications may impact your sexual health. Pregnancy in IBD is safest when planned with your IBD team. You or your doctor may prefer some birth control options that are best for your needs. All IBD patients, male and female, should discuss the HPV vaccine and how to reduce your risk of sexually transmitted diseases.

EYE CARE

Go if you've ever been on steroids (e.g. Prednisone), or if your doctor recommends you get an eye check for any reason.



BASIC SCREENING TESTS TO BE PROACTIVE ABOUT

BLOOD TESTS

May need to be on a regular schedule (e.g. every 3-6 months) to monitor medication response and prevent dangerous side effects if you're on certain medications. Talk to your IBD team and be proactive about asking for lab orders or scripts when you think it's time.

DEXA BONE DENSITY SCAN

IBD patients with risk factors for bone loss may need special X-rays of their bones taken periodically. Ask your care team whether you might need this.

SCOPES

Generally, colonoscopies screening for cancer need to occur periodically starting after 8-10 years of colonic disease, but some situations require an earlier start. Check with your doctor about the frequency of yours.



THINGS TO AVOID

The best part of adult care is having my opinion valued more. My GI asks what I think of my medications and treatments. - Rebecca



NSAIDS (ASPIRIN, IBUPROFEN, NAPROXEN)

Most non-steroidal anti-inflammatory drugs (NSAIDs) carry a risk of GI inflammation, even to a person without IBD. This risk is elevated in people with IBD. Talk to your care team about what other pain and/or fever medications are safe for you to use.

SMOKING

Smoking and non-smoked tobacco products are especially bad for people with IBD. These are known to trigger disease activity, increase the need for surgery, and impair both intestinal and surgical healing.

STREET DRUGS

In addition to the other risks of using illicit substances, drugs can put strain on the liver, which may also be affected by your treatment. Always inform your doctor of any substances you use (even herbals and homeopathics!).



ASK YOUR IBD TEAM ABOUT THESE

ALCOHOL

Alcohol can be harmful to the GI tract and liver in IBD, even in small amounts. With some medications (including metronidazole and methotrexate), alcohol can cause severe symptoms.

LIVE VACCINES

Live vaccines are unsafe with some IBD medications, particularly those that suppress the immune system. Be sure to ask which vaccines, like an annual flu shot, you **SHOULD** get!



I keep a file where I list my current medication doses, a brief medical history, my questions, and a social history (which I always keep at the top of the page so the reader has to learn about who I am beyond my disease!). This structure helps me interact with my doctor and record her answers so I can later communicate that information to my family and other doctors. - Jennie

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TRANSFER RESOURCES TO TRY



MyHealth Passport

www.sickkids.ca/myhealthpassport/

Here you can create a personalized wallet-sized card that gives an instant glimpse into your medical history.

The Center for Children with Special Healthcare Needs

www.cshcn.org/planning-record-keeping/documents

This website contains planning documents and care summary templates for young adults getting ready for transfer.

GotTransition (The National Alliance to Advance Adolescent Health)

www.gottransition.org

This resource has a wealth of information for and stories by young adults with chronic illnesses making the move to adult care.

JustLikeMeIBD (The Crohn's and Colitis Foundation)

www.justlikemeibd.org

This website's Preparing for Adult Care section includes great videos and infographics.

I would recommend using an electronic or paper journal to track your symptoms and/or nutrition. This information is invaluable for reference when at the doctor. - Grady



Doc4Me (created by NASPGHAN)

Create a personalized readiness checklist using this app. Basic info about nearby doctors is available to browse.

Symptom Tracking Apps like...

myIBD, Plop, Flaredown, Symple, Bowelle, Cara

ACKNOWLEDGMENTS Thank you to the following organizations who inspired, informed, or helped develop content for The Transfer Toolkit:



Throughout this Toolkit, you've read stories from young adults living with IBD. We all belong to the ImproveCareNow Patient Advisory Council, a group of activists in our teens and twenties who help make IBD care better for young people like us. To get involved, visit www.improvecarenow.org/patients.

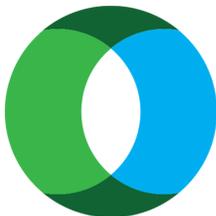


Please help us make the Transfer Toolkit better.

If you have IBD and see a pediatric gastroenterologist, please answer a few questions at :

bit.ly/IBDTransfer

or scan the QR code above.



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