UW Medicine UNIVERSITY OF WASHINGTON MEDICAL CENTER

Inflammatory Bowel Diseases Clinic

At Harborview Medical Center

Welcome

Thank you for choosing the Inflammatory Bowel Diseases Clinic at Harborview Medical Center (HMC) for your care. We offer care for patients who have inflammatory bowel diseases (IBD), including Crohn's disease and ulcerative colitis.

Our IBD Clinic uses advanced imaging procedures to assess and treat IBD. We also offer promising new therapies as part of research studies that test new treatments.



The Inflammatory Bowel Diseases Clinic is on the 7th floor of the Maleng Building at Harborview Medical Center.

Getting Started

Please carefully read this handout. Be sure to write down any questions that you have. Bring these questions with you to your next clinic visit.

Your Care Team

At the clinic, you will receive high-quality care from a team of care providers. Your care team includes:

- You, the patient: You are a vital member of your healthcare team. The more you learn about your disease and your treatment, the better your results will be. Help us by keeping in touch with our clinic and following your treatment plan.
- **Doctor:** Dr. Afzali, Director, Inflammatory Bowel Diseases Program
- Clinic nurse: Katie. RN
- Clinic coordinator and scheduler: Lara
- Pharmacy staff: A pharmacist and pharmacy tech will help you with medicine authorizations and approvals for many of the medicines you will need.

• **Dietary staff:** A nutritionist who specializes in IBD will help make sure your diet is providing you with all the nutrition you need.

Your Treatment Plan

IBD is a chronic, life-long disease. There is no cure for IBD, but it can often be controlled by medicines and lifestyle changes.

Dr. Afzali and her team will work with you to create your personal treatment plan. As the patient, you must be fully committed to your care plan for it to work. We will work closely with you to help you to stay on track with your care plan and help you in any way we can.

We know that living with IBD has both physical and emotional challenges. In creating your treatment plan, we will focus on improving your health, nutrition and overall quality of life. Your care plan will include education, support and counseling.

Our Goals for Your Treatment

Our goals for your treatment are to:

- Soothe the inflammation in your intestines
- Control your symptoms and reduce *flares* (times when the symptoms are strong, also called *flare-ups*)
- Avoid complications and hospital stays
- Lower your need for surgery, steroids, or both
- Improve your quality of life

Other Treatment Options

- **Surgery:** Our IBD team works with colorectal surgeons from Harborview Medical Center and University of Washington Medical Center. If you need surgery to treat your IBD, Dr. Afzali will talk with you about this option.
- Clinical Trials: These research studies test new treatments or medicines that are not yet approved for general use. Clinical trials may be a treatment option for some IBD patients. If a clinic trial is right for you, Dr. Afzali will talk with you about this option.

Your First Clinic Visit

Our IBD Clinic is on the 7th floor of the Maleng Building, 325 9th Ave., Seattle, WA 98104. Our phone number is 206.744.8845.

Please arrive 15 minutes before your appointment time. If you are more than 15 minutes late for your appointment, we may need to reschedule your appointment for another day.

Please bring these things with you to your first clinic visit:

- Your current insurance card(s)
 - Note: If your insurance changes during your treatment, call Clinic Registration at 206.744.8845 with your new insurance information.
- A photo ID (driver's license, passport, or military license)
- Copay(s), if your insurance requires them
- · A list of medicines you are currently taking
- Your immunization records
- Your primary care provider's contact information

Your Medical Records

Before your first visit, fax us all medical records related to your IBD and the treatments you have had. Our fax number is 206.744.6095. Mark the fax "Attn: Katie or Lara."

Cancelling Your Appointment

- If you need to change or cancel an appointment, please call 206.744.2788 at least 72 hours (3 days) before your appointment.
- If you do not call to cancel, you may be charged for part of the visit.
- If you cancel too many appointments or procedures, or if you do not keep your appointments and do not cancel them ahead of time, we may not be able to schedule you for future appointments.

Questions About Your Bill

If you have any questions about a bill that you receive from our clinic, please call Financial Services at 206.744.3084.

Diagnosing Your IBD

Imaging Scans

We use different types of imaging to help diagnose your IBD. These include:

- X-rays
- Magnetic resonance imaging scans (MRIs)
- Computed tomography (CT) scans

We use these same scans during your treatment to see how well you are doing.



If you need to change or cancel an appointment, call the clinic at least 3 days before your appointment.

Colonoscopy

You will need to have a procedure called a *colonoscopy* as part of your care plan. In a colonoscopy:

- A long, flexible, tube with a tiny camera on the end is used to view the inner lining of your colon (large intestine) and your rectum.
- Small pieces of tissue (biopsies) are taken from the inside of your colon.
 These will be looked at under a microscope by a pathologist (a doctor who examines body tissues to diagnose disease).

These biopsies will help us know:

- How severe your disease is
- What areas of your bowel are affected
- How well your treatment is working
- If you have any signs of IBD after surgery (if you have surgery)
- If you have cancer in your colon or rectum

Esophagogastroduodenoscopy

You may also need to have an *esophagogastroduodenoscopy* (EGD) or an *upper endoscopy*. These tests will show if your upper digestive tract (*gastrointestinal* or GI tract) are affected by your IBD. The upper GI tract includes your *esophagus* (the tube that goes from your throat to your stomach), stomach and *duodenum* (the first part of your small bowel).

Medicines

We cannot cure IBD, but we can help keep your symptoms under control with medicines. You must take your medicines the way they are prescribed, or your treatment may not work.

If you stop taking your medicines or do not take them regularly, your body can build up *immunity* to the medicines. If this happens, your body will no longer accept the medicine and your IBD may get worse. This can result in needing to stay in the hospital overnight, missing work, and a poorer quality of life. If your disease gets much worse, you may need surgery.

Blood Tests

You will need blood tests from time to time to check how well the IBD medicines are working. How often you need these tests is based on the medicines you are taking. Dr. Afzali will talk with you about this more at your clinic visits.

Our clinic nurse will help keep track of your blood test schedule. Call Katie at 206.744.1293 if you have any questions.



Remember that it takes 2 to 3 days for the pharmacy to process your refill order.

Medicine Refills

Please closely watch your medicine supply. **You need to call us at least 48 to 72 hours before your prescription runs out**. It takes the pharmacy 48 to 72 hours (2 to 3 days) to process your refill order.

We will be happy to refill your prescription. If you need help with your refill:

- Call Katie at 206.744.1293.
- Or, have your pharmacy fax a refill request to 206.744.6095, Attn: Katie.

Immunizations

Your IBD team recommends that you have these immunizations (vaccines):

Vaccine	How Often	Notes
Flu (influenza)	Every year	Do NOT get the live form of this vaccine (see "If You Take Immunosuppressive Medicines" below)
Pneumonia (pneumovax)	Every 5 years	
Tetanus, Diptheria and Pertussis (TDap)	Every 7 to 10 years	
Hepatitis A	One time	This is a 2-step series
Hepatitis B	One time	This is a 3-step series
Human papilloma virus (HPV)	One time	For patients under 26 years old
Meningoccal	One time, plus one booster 3 to 5 years later	For patients under 26 years old

If You Take Immunosuppressive Medicines

If you take any medicines that suppress your immune system:

- Do **not** get live vaccines.
- Tell all your healthcare providers that you take immunosuppressants.
- If a family member or someone you live with needs to receive a live vaccination, ask your PCP or your family member's PCP what to do to make sure you stay healthy.



A nutritionist who specializes in IBD will work with you to create your eating plan.

Diet and Nutrition

Even though we cannot cure IBD, you can help control your IBD symptoms by eating some foods and avoiding others. You will see an IBD nutritionist as part of your treatment at the clinic.

Your nutritionist will work with you to create an eating plan that is specially designed for you. We will also give you handouts on IBD and nutrition.

Supplements

With IBD, your intestines can become inflamed. This makes it hard for them to absorb some of the nutrients in the foods you eat. You may need to take supplements to help you get these nutrients. We will check the levels of these nutrients in your blood and prescribe supplements as needed.

These are some of the nutrients we look for in your blood tests:

- Iron
- Folate (folic acid)
- Vitamin D
- Vitamin B12
- Zinc

These nutrients help your body make red blood cells. When the body does not absorb these nutrients, you can have *anemia* (low number of red blood cells). Anemia is one symptom of IBD. Inflammation, blood loss or diarrhea can make anemia worse.

Things to Avoid

To help ease your IBD symptoms:

- Do not take non-steroidal anti-inflammatory drugs (NSAIDs). These
 medicines irritate your GI tract. NSAIDs include aspirin, ibuprofen
 (Advil, Motrin and others), and naproxen (Aleve, Naproxyn and
 others).
- Do not smoke or use tobacco.
- Do not use live vaccines.

If You Smoke

Smoking can make Crohn's disease worse. Smoking also increases your risk of cancer. If you smoke and would like to stop, we can give you resources to help you quit. Please ask your nurse for more information.

Your Primary Care Provider

- The IBD Clinic is a specialty clinic. We do not provide many of the
 healthcare services that you expect to receive from a primary care
 provider (PCP). A PCP is the healthcare provider you see for your
 general health care. Even though you are receiving treatment at our
 clinic, you must also keep in close contact with your PCP.
- Please make sure that we also have your PCP's contact information. We will keep in contact with them about your care and treatment plan at our clinic.
- If you do not have a PCP, please tell us. We will be happy to refer you to a PCP at Harborview's Adult Care Clinic.

Follow-Up Visits

The timing of your follow-up visits at the IBD clinic will depend on your personal treatment plan. You will likely have follow-up visits at least every 6 to 12 months. Most patients come to the clinic more often than this.

- Please call your IBD nurse at 206.744.1293 if you have any medical questions, concerns, or your symptoms are getting worse.
- Please call your IBD coordinator at 206.744.2788 if you want to schedule an appointment, procedure or infusion, or if you need to cancel or reschedule an appointment.

To Learn More

Visit these websites to learn more about inflammatory bowel disease and it treatments:

- University of Washington Division of Gastroenterology website: www.uwgi.org/ibd
- Crohn's & Colitis Foundation of America website: www.ccfa.org
- You and IBD website: www.youandibd.com

Important Phone Numbers

Clinic Registration (if your insurance changes)	. 206.744.8845
Inflammatory Bowel Diseases Clinic	. 206.744.8845
Financial Services.	206.744.3084
IBD Nurse (Katie)	206.744.1293
IBD Coordinator (Lara)	206.744.2788
IBD Fax (Attn: Katie or Lara)	206.744.6095



Thank You

It is a privilege to be involved in your medical care. Thank you for choosing the Inflammatory Bowel Disease Clinic at UW Medicine - Harborview Medical Center.

Dr. Anita Afzali, Director Inflammatory Bowel Diseases Program

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Inflammatory Bowel Diseases Clinic: 206.744.8845