

KNOW YOUR IBD
WEBCAST SERIES FOR PATIENTS

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UNDERSTANDING Crohn's Disease

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Today's Program will...

- Help you understand Crohn's disease and its effects
- Review current treatments, including medications and surgery
- Provide tips for managing your disease
- Share resources to answer your questions and provide support

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Poll Question #1

Which best describes you?

- A) I am a patient with Crohn's disease
- B) I am a family member of a patient with Crohn's disease
- C) I am a friend of a patient with Crohn's disease
- D) I am unsure if I have Crohn's disease
- E) No connection, just want more information

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What is Crohn's Disease?

- Belongs to a group of conditions known as inflammatory bowel diseases (IBD)
- Chronic inflammatory condition of gastrointestinal (GI) tract
- Patchy, full thickness of intestinal wall
- Mouth to anus, mostly end of small intestine and colon
- Affects estimated 700,000 Americans
- Symptoms and prognosis differ for each person



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Symptoms

- Diarrhea
- Bloody stool
- Abdominal pain
- Appetite or weight loss
- Fatigue



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Potential Complications

May include:

- Strictures
- Internal fistulas
- Perianal involvement
- Colon cancer
- Malnutrition
- Decreased growth and development

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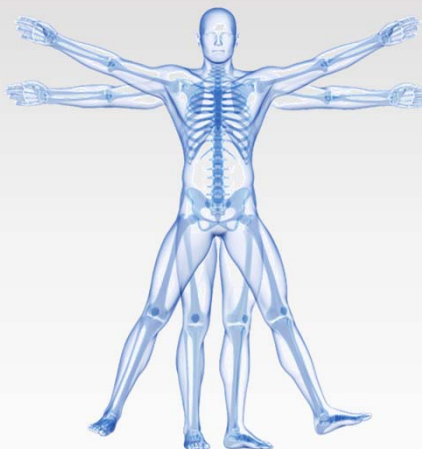
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Extra-intestinal manifestations

May include:

- Eyes
- Mouth
- Joints
- Skin
- Bones
- Kidneys
- Liver



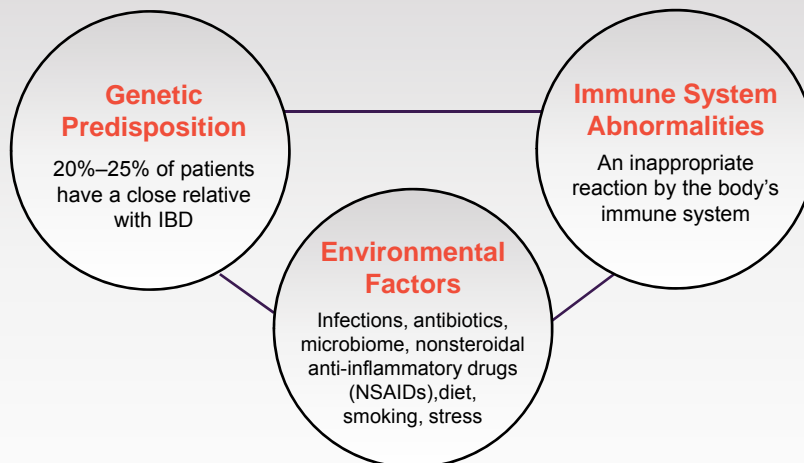
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What Are the Potential Causes?



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Location, Location, Location

- Ileal involvement 33% of patients
- Colon involvement 20% of patients
- Ileocolonic disease 45% of patients
- Isolated upper tract disease <5%

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Patterns of Disease

- Inflammatory Crohn's disease
 - Inflammatory changes in the lumen
- Stricturing Crohn's disease
 - Flares and remission
 - Strictures, or narrowing of intestine
- Perforating (fistulizing) Crohn's disease
 - Fistulas, or tunnel-like formations
 - May include perianal involvement

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Treatment Goals

Induction of Remission

- Turning "off" the inflammation
- Feeling well, improving quality of life
- Normalization of labs, growth, development and nutrition

Maintenance of Remission

- Disease control and optimization of therapy
- NO STEROIDS
- Prevention of relapse over time
- Changing the natural course of the disease


Disease Monitoring and Prevention

- Monitoring for early relapse
- Monitoring therapies
- Prevention of infections
- Cancer prevention

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Medications

- Over-the-counter
- Antibiotics
- Aminosalicylates
- Corticosteroids
- Immunomodulators
- Biologics



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Poll Question #2

My treatment regimen includes:

- A) Corticosteroids
- B) Aminosalicylates
- C) Immunomodulators
- D) Biologics
- E) Antibiotics
- F) Two or more of the above

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Over-The-Counter (OTC) Medications

Over-the-counter

Antibiotics

Aminosalicylates

Corticosteroids

Immunomodulators

Biologics

- Address symptoms only
 - Anti-diarrheal agents
 - Laxatives
 - Pain Relievers
- NSAIDs may cause or worsen GI irritation
- Talk with your physician *before* taking OTC meds
- Complementary and alternative medicine
 - Vitamins
 - Minerals
 - Supplements

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Antibiotics

Over-the-counter

Antibiotics

Aminosaliclates

Corticosteroids

Immunomodulators

Biologics

- Effective for
 - pouchitis
 - perianal fistulas
 - abscesses
- Bacterial resistance
- Associated with flares
- Antibiotic-associated diarrhea and *Clostridium difficile*

Medications:

- Metronidazole (Flagyl®)
- Ciprofloxacin (Cipro®)
- Rifaximin (Xifaxan®)

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Aminosaliclates

Over-the-counter

Antibiotics

Aminosaliclates

Corticosteroids

Immunomodulators

Biologics

- Effective for mild–moderate disease
- Few serious side effects
- Releases medication to specific areas of bowel

Medications:

- Sulfasalazine (Azulfadine®) Oral
- Mesalamine (Apriso®, Delzicol®, Lialda®, Pentasa®, Rowasa®) Oral or Rectal
- Olsalazine (Dipentum®) Oral
- Balsalazide (Colazal®, Giazol®) Oral

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Corticosteroids

Over-the-counter

Antibiotics

Aminosalicylates

Corticosteroids

Immunomodulators

Biologics

- Initially effective in inducing remission
- Risks include
 - Infection
 - Sleep disturbance and mood swings
 - Neurological changes
 - Changes in physical appearance
 - Growth delays and bone loss

Medications:

- Budesonide (Entocort®, Uceris®) Oral
- Hydrocortisone (Cortenema®, Cortifoam®)
 - Enema, oral, intravenous
- Methylprednisolone (Medrol®) Oral or intravenous
- Prednisone, Oral

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Thiopurine Immunomodulators (Azathioprine, 6-MP)

Over-the-counter

Antibiotics

Aminosalicylates

Corticosteroids

Immunomodulators

Biologics

- Steroid-sparing agents, used in maintenance
- Can be taken with other medications to induce remission

Risks

- Can be individualized (TPMT genotype)
- Fever
- Pancreatitis
- Low white blood cells
- Elevated liver tests
- Infection (viral)
- Lymphoma (EBV-associated)

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Immunomodulators (cont)

Over-the-counter

Antibiotics

Aminosalicylates

Corticosteroids

Immunomodulators

Biologics

- Methotrexate
 - Oral and injection
- Recommended if other medications have been ineffective
- May be helpful in improving fistulas
- Need daily folic acid intake
- Common side effects: nausea, headache, and fatigue
- Not to be taken during pregnancy, or by men or women planning conception

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Biological Therapies

Over-the-counter

Antibiotics

Aminosalicylates

Corticosteroids

Immunomodulators

Biologics

- Block inflammation or stimulate anti-inflammation
- Similar to biologic chemicals in body
- Effective for patients who
 - Do not respond to standard therapy
 - No longer respond to standard therapies
- Risks include
 - Infections
 - Infusion or injection site reactions
 - Lupus, MS, and psoriasis-like reactions
 - Increased risk of melanoma

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Biological Therapies (cont)

Over-the-counter

Antibiotics

Aminosalicylates

Corticosteroids

Immunomodulators

Biologics

Anti-TNF

- Adalimumab (Humira®) Injection
 - Newly approved pediatric indication
- Certolizumab pegol (Cimzia®) Injection
- Infliximab (Remicade®) Intravenous

Selective adhesion molecule

- Natalizumab (Tysabri®) Intravenous

Integrin Receptor Antagonist

- Vedolizumab (Entyvio™) Intravenous

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Medication Considerations in Special Populations

- Each medication presents benefits and risks
- Children require special considerations
 - 10% of people affected by IBD are under the age of 18 and require individualized treatment
 - Few clinical trials have addressed efficacy and dosage in children
 - Treatment approaches for children are largely based on adult experience
- Some medications, including methotrexate, may be contraindicated in pregnant women (but most are OK)

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Judging Response to Treatment

- How do I know if my treatment is working?

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Judging Response to Treatment

- How do I know if my treatment is working?
- If I am in remission, should I stop my treatment?

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Judging Response to Treatment

- How do I know if my treatment is working?
- If I am in remission, should I stop my treatment?
- How much time should I allow before trying a new medication?

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Surgical Options

- Surgery and medication can combine for better quality of life
- Primary goals of surgery
 - Alleviate complications
 - Alleviate symptoms
 - Achieve best possible quality of life
 - Bowel conservation

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Surgical Options

- Stricturoplasty
- Intestinal resection
- Colectomy (partial or complete)
- Proctocolectomy
- Diverting colostomy or ileostomy
- Cannot be cured with surgery

ANATOMY OF THE ABDOMEN

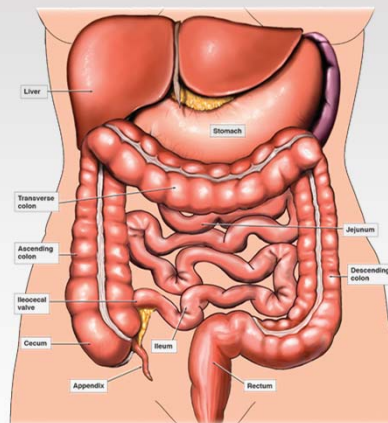


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Elective and Emergency Surgery

Elective

- Stricture
- Failure of medication to control disease
- Formation of a fistula or abscess
- Dysplasia

Emergency

- Perforation of the bowel
- Intestinal obstruction or blockage

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Critical Role of Nutrition

- “Diet” = the food you eat on a daily basis
- “Nutrition” = how your body uses nutrients from your diet
- No known diet alters inflammation
- Certain foods for individual patients may exacerbate symptoms during a flare
- Keep a food diary
 - www.ccfacommunity.org



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Good Nutritional Choices

- Good nutrition is key to:
 - Healing, immunity, and energy levels
 - Preventing or minimizing GI symptoms

Recommended Foods	Recommended Supplements
Carbohydrates with more soluble fiber (oat brans, legumes, barley)	A daily multivitamin
Protein (eggs, lean meats, smooth nut butters)	Vitamin B12 (monthly injection may be given to patients with ileitis)
Well-cooked fruits and vegetables	Calcium, Vitamin D
Healthy fats (canola or olive oil)	Folic acid

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CAM

- National Center for Complementary and Alternative Medicine categories
 - Natural products (e.g., supplements and probiotics)
 - Mind and body medicine (e.g., meditation and acupuncture)
 - Manipulation and body-based practices (e.g., massage and spinal manipulation)
- Of interest to Crohn's patients because
 - Medications do not perfectly control disease
 - Difficult symptoms
 - Side effects of medications
- Can be used as adjunctive therapy to conventional therapy; rarely will it be a sole treatment

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Probiotics

- "Good" bacteria claims to "restore" balance in gut
- Limited studies on effectiveness
- Do NOT treat active Crohn's disease
- Strains
 - VSL#3®
 - *Escherichia coli* Nissle 1917 (Mutaflor®)
 - *Lactobacillus acidophilus* (Flora-Q®)
- Discuss with physician before initiating treatment

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Poll Question #3

Have you used complementary and alternative medicine for Crohn's in addition to medications

- A) Yes
- B) No

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Monitoring Crohn's Disease

- There is no one test to diagnose Crohn's disease
- You may have one or more tests and procedures:
 - Blood and stool tests
 - Endoscopy
 - External imaging

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Blood and Stool Tests

- Check medication levels
- Test function of body systems and response to treatment
- Monitor risk of infection
- Look for abnormalities
- Include:
 - Complete blood count
 - Comprehensive metabolic panel (CMP)
 - C-reactive protein (CRP)
 - Erythrocyte sedimentation rate (ESR)
 - Fecal calprotectin (FCP)



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Endoscopic Procedures

Endoscopic Procedure	Observation
Colonoscopy	<ul style="list-style-type: none"> • Insert through anus • Observe rectum, colon and lower small intestine • Fasting
Flexible sigmoidoscopy	<ul style="list-style-type: none"> • Shorter scope • Lower colon • Enema before procedure
Capsule endoscopy	<ul style="list-style-type: none"> • Swallow camera capsule • Difficult areas to reach
Upper endoscopy (EGD)	<ul style="list-style-type: none"> • Upper abdominal pain • Nausea • Vomiting • Difficulty swallowing
Endoscopic ultrasound (EUS)	<ul style="list-style-type: none"> • Ultrasound images below surface of gut • Fistulas in rectal area

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External Imaging Procedures

Imaging procedure	Observation
Computed tomography (CT, CTE)	X-ray images at various angles May include contrast
Magnetic resonance imaging (MRI)	<ul style="list-style-type: none"> • Soft tissue images with magnetic waves • Small intestine and other areas
Small bowel imaging (SBFT, SBS)	Swallowing barium Evaluates small intestine
Barium enema	Barium placed directly in colon Colon distended with air
White blood cell scans	Detect WBC in intestinal tissue Cause of inflammation
Ultrasound	High-frequency sound waves
X-rays	Detect blockages in small or large intestine

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Tips to Prepare for Your Doctor's Visit

- Know any preparatory instructions prior to visit
- Make prioritized list of questions
- Write down symptoms and side effects
- Bring someone you trust with you
- Carry a timeline list of
 - Medications and dosage (present and past)
 - Include vitamins/supplements
 - Prescribing physician and contact info
 - Hospitalizations and surgeries
 - Life event changes
- Use tools to help keep track
- Bring item to keep you relaxed during your wait



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Poll Question #4

How comfortable do you feel discussing concerns about managing Crohn's disease with your doctor?

- A) Very comfortable
- B) Comfortable
- C) Somewhat comfortable
- D) Not comfortable at all



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Strengthen Communication with Your Doctor

Questions to Ask Your Doctor

- What parts of my bowel are affected?
- What treatment plan is suitable for me?
- Would you recommend probiotics?
- What side effects from medication may occur?
- How soon do symptoms subside?
- Should I change my diet or take supplements?
- Are there any restrictions on my activities?
- How often do I need a follow-up colonoscopy?

The guide can help you and your doctor see how inflammatory bowel disease (IBD) is affecting you, and if you could be doing more to manage your life. Over the years, compare the first part, and bring the guide with you to your next appointment.

Share the following information with your doctor:

- During the past 6 weeks, I had the following average number of stools or bowel movements per day. How many times in total I had more than 3 stools or more than 3 bowel movements.
- Over the past month, I would rate the severity of my abdominal pain as: None at all, Mild, Moderate, or Severe.
- For experienced the following average number of flare-ups over the past year. How often did you experience flare-ups that led to hospitalization or other medical attention (e.g., surgery, IV therapy, or other treatments)?
- Since my last visit, I've experienced the following IBD symptoms:
- For show the following things to avoid at least once a week (e.g., alcohol, stress, or other social engagements, avoid activities I enjoy).
- Experiencing IBD has affected me in the following ways:

For experienced the following changes in appetite, and or body weight over the past 6 months:

- For experienced the following complications over the past month (e.g., joint pain, skin lesions, eye lesions, hair or falling, etc.):
- For experienced the following complications over the past month (e.g., joint pain, skin lesions, eye lesions, hair or falling, etc.):
- Since starting my current treatment, my disease symptoms have improved in the following ways. How often have you experienced side effects with your current treatment (show below if any):

Bring to questions to ask your doctor:

- Which treatment options may be right for me?
- What are the benefits and possible side effects of these options?
- How long might it take before I see an improvement in my symptoms?
- What can I do to prevent the getting the most from my medication?
- What else can I do, in addition to taking my medication, to effectively manage my IBD?

www.crohn.org | www.colitis.com



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Key Points on Crohn's Disease

- Inflammatory condition of GI tract with patchy, full thickness of intestinal wall
- Symptoms and prognosis differ for each person
- Know the goals of your treatment strategies
- Talk to your doctor about monitoring your disease
- Prepare for your visits – create checklists for your care
- Have open communication with your healthcare team

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References

References

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- CCFA website: www.cdfa.org/resources/types-of-medications.html
- Rubin, DT. *Treatment Options in IBD* webcast: www.cdfa.org/resources/IBD-treatments-webcast.html
- Kane S. *IBD Self-Management: The AGA Guide to Crohn's Disease and Ulcerative Colitis*. Bethesda, MD: AGA; 2010.
- National Center for Complementary and Alternative Medicine:
<http://nccam.nih.gov>

Additional Resources

- Treatment and Self-Management: <http://www.ibdetermined.org/>
- Community Site: <http://www.ccfacommunity.org/>
- Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center):
888.694.8872 or info@ccfa.org

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QUESTIONS?

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AGA Resources

- Education :
<http://www.gastro.org/patient-center/digestive-conditions/inflammatory-bowel-disease>.
- Patient guide to GI procedures:
<http://www.gastro.org/patient-center/procedures>
- Patient guide to diets and medications:
<http://www.gastro.org/patient-center/diet-medications>

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CCFA Resources



- Irwin M. and Suzanne R. Rosenthal IBD Help Center
M-F, 9:00 AM-5:00 PM ET
 - Phone: 1-888-694-8872
 - Email: info@ccfa.org
- Educational webcasts: www.ccfa.org/resources/webcasts.html
- Connect with other patients
 - CCFA Community website: www.ccfacommunity.org
 - Support groups and Power of Two (peer mentors):
– www.ccfa.org/chapters
- GI Buddy: online tracking tool and mobile app www.ccfa.org/gibuddy
- Local educational events, visit: www.ccfa.org

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CCFA Partners



- Registry of patient-reported outcomes
- Available for pediatric and adult patients

www.ccfapartners.org

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Get Involved!

TeamChallenge
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TAKE STEPS
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WWW.CCTAKESTEPS.ORG

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