Top 10 Things you need to know about IBD

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Top 10 Things to Know: IBD

- What you can eat
- How to treat the pain
- Not all diarrhea is a flare
- Ways to reduce your risk of getting cancer
- Smoking and IBD
- Know the benefits and risks of medications
- How long you will need to take the medications
- Ways to prevent antibody formation
- The IBD Timeline: Keep track of your records
- Don’t forget about health care maintenance
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What you can eat

- If there is a narrowing or blockage in the bowel: use a low residue diet (avoiding roughage and foods high in fiber)

- Many fad diets and other diets have anecdotal evidence

- To date, Western medicine does not support any particular dietary modification for IBD.

- Food in general is mildly irritating to Crohn’s disease
  - IV nutrition or elemental diets are better for Crohn’s but are not practical
  - Exclusion diets have not yielded any specific exclusion diet that is helpful.

- Bottom line: Unless you have a blockage, eat what feels OK and avoid what doesn’t

- Important not to restrict calories when the disease is active
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Causes of pain in IBD

Abdominal:
- Inflammation
- Narrowing/blockage
- Infection
- Irritable bowel syndrome (IBS)
- Pancreatitis- gallstones or from medication

Other pains: Joints, eyes, anal
How to treat the pain

- Step #1: identify the cause of the pain: not all pain is IBD related
- Step #2: Treat the underlying cause
  - Intestinal inflammation?
  - Blockage?
  - Medication side effect?
- Step #3: If medications aren’t working and the pain is due to IBD, consider surgery
How to treat the pain

- Non steroidal anti-inflammatories (NSAID)s: can trigger a flare (Ibuprofen, Motrin, Aleve, Naprosyn, Mobic)
  - If must be used, consider COX-2 selective inhibition (celecoxib/Celebrex)

- Narcotics: Associated with increased rates of infection and death in outpatients with Crohn’s disease, could cause a dilated colon

- Acetaminophen (Tylenol) at certain doses, tramadol OK

- Anti spasmodics (Levsin, Bentyl)
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Not all diarrhea is a flare

- Infection
  - Bacterial infection (including C. Diff)
  - Viral infections (Norovirus, CMV)
  - Parasite

- Celiac disease

- Small bowel bacterial overgrowth

- Bile acid diarrhea

- Other
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Ways to reduce your risk of getting cancer

- Colon cancer
  - Reduce inflammation by taking medications as prescribed
  - Surveillance program (serial colonoscopies) if > 1/3 of colon for >8 years: if several precancerous areas found surgery may be recommended
  - Controversial for preventing colon cancer: mesalamine, azathioprine (Imuran) or 6MP, calcium, aspirin, folic acid

- Skin cancer
  - Sunblock, minimize sun exposure
  - Annual skin exams if you are on 6MP or azathioprine
  - Talk about your skin cancers with your gastroenterologist!
Ways to reduce your risk of getting cancer

- Cervical cancer
  - Annual pap smears if immunocompromised
- Minimize # of CT scans if possible especially if you are young (theoretical risk of radiation leading to cancer)
- Don’t Smoke
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Smoking and IBD

- Smoking is a risk factor for Crohn’s disease
  - Causes flares
  - Is a risk factor for the need for surgery
  - Quitting works better than any treatment we have

- Smoking is protective in ulcerative colitis
  - We DO NOT recommend smoking because of all of the other harmful effects of smoking
  - Nicotine patch does not work as a maintenance therapy in UC

- Cannibis: makes you feel better (big surprise), but new data show higher rates of surgery in Crohn’s

Storr M. Inflamm Bowel Dis. 2014 Mar;20(3):472-80
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Know the benefits and risks of medications

- Improves quality of life
- Treats diarrhea
- Treats pain
- Improves nutrition
- Prevents complications
- Prevents hospital stay
- Prevents surgery
- Prevents cancer

- Costs
- Side effects
- Infection
- Worsening symptoms
- Pancreatitis
- Cancer
- Unknowns
Have a conversation with your doc

- Define your goals of therapy
- Ask your doctor to define his/her goals
- What is the likelihood of this medication working on me?
- What is the chance of a side effect?
- If I don’t take the medication what could happen?
- Make the decision together based on this

Example goals
• Feeling better
• living a long healthy life
• Avoiding surgery
• Minimizing side effects
Side effects/Risks of medication

- **5ASA**: headache, rash, alopecia, *interstitial nephritis*, pericarditis, pneumonitis, hepatitis, pancreatitis, **worsening diarrhea and abdominal pain**

- **Azathioprine/6-MP**: nausea, allergic reaction, **pancreatitis**, *bone marrow suppression*, drug induced hepatitis, *infection*, *lymphoma*, non-melanomatous skin cancer

- **Methotrexate**: rash, **nausea**, mucositis, diarrhea, *bone marrow suppression*, hypersensitivity pneumonitis, **elevated liver enzymes/hepatotoxicity**, hepatic fibrosis, cirrhosis, **must be used with 2 forms of contraception**

- **Anti-TNF antibody**: infusion reactions, delayed hypersensitivity reactions, new or worsening heart failure, injection site reactions, auto-antibody formation, drug-induced lupus, demyelinating disorders, Non Hodgkins *lymphoma*, *infection* (including but not limited to tuberculosis, histoplasmosis, coccidiomycosis, listeriosis)

- **Steroids (prednisone)**: bruising, infection, elevation in blood pressure, behavioral changes, stretch marks, weight gain, insomnia, long term use has been associated with higher rates of death, osteoporosis, cataracts, osteonecrosis
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How long you will need to take the medications

- High chance of flaring if stop infliximab (>40% in 1 year)
- The answer is never forever. Forever is a long time
- Yearly re-evaluation
  - Re-evaluate goals
  - Re-evaluate new knowledge on the medications
  - Are there new medications with better results or less side effects?
- Important to not lose a medication that works! Starting and stopping could make the medication less likely to work
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Ways to prevent antibody formation

WHAT’s an ANTIBODY? An **antibody** is a protein produced by the body's immune system when it detects foreign substances, called antigens.

If you are taking a BIOLOGIC medication (Remicade, Humira, Cimzia, Stelara, Simponi) your body could make antibodies against the medication which makes the medication ineffective. Here are some strategies to help prevent this from happening:

- Don’t stop the medication against a doctor’s advice
- Don’t skip or delay doses
- Talk to your doc about using Imuran, 6MP, or methotrexate along with the biologic to reduce the chance of antibodies
- Get a steroid injection 30 minutes before your Remicade infusion
- Antibodies can now be measured for Remicade and Humira
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The IBD Timeline: Keep track of your records

- Some patients have one doctor for their IBD for their life but many have multiple providers throughout their life.

- Each time you meet a new doctor they need to know your history, and obtaining records can be challenging for all involved.

- I recommend keeping a timeline—ask for help from your doctor to keep this updated every year.

- If your doctor doesn’t know what you have been through in the past, they are less likely to be able to prevent it from happening again.

- Confirm the timeline with your old doctor, show this timeline to your new doctor. It will save time, money, grief, side effects, and improve your care!
My IBD Timeline

- Level of detail- up to you
- Dates of major events
- Date of diagnosis with doctor name
- UC or Crohn’s?
- Names of medications tried and effect- good or bad, include doses and side effects
- Location: esophagus, duodenum, jejunum, ileum, colon
- Severity: mild, moderate, severe
- Perianal fistulas, rashes, joint problems, eye problems
- Procedures, Complications, Hospitalizations, Surgeries
My IBD Timeline: sample

- Sarah Smith DOB 6/8/90
- 2010 rectal bleeding- Diagnosed with ulcerative colitis on sigmoidoscopy, started on prednisone and mesalamine
- 5/2011 colonoscopy- showed severe inflammation from rectum to transverse colon
- 3/2012 flare- required steroids, hospitalized, antibody to Remicade discovered, Remicade stopped
- 3/2012- Humira started, worked modestly, increased to weekly dosing then worked well.
- 2014- flare again, surgery done (subtotal colectomy, Brooke ileostomy)
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- It’s important to keep the intestines healed....
- But don’t forget to keep the rest of you healthy!
- IBD Cornerstones Patient Checklist: google it!