10 facts every patient with Inflammatory Bowel Disease should know!

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Inflammatory Bowel disease

- IBD: Crohn's disease and ulcerative colitis
- Crohn's disease:

  Can affect gut from mouth to the anus

  Most commonly the last part of the small intestine, terminal ileum
- Ulcerative colitis:

  Colon only
- If we cannot differentiate the 2:

  Indeterminate colitis

1. You should know the exact location of your IBD

How much of YOUR intestine is affected?

- It is important that you know this information
  So ask your doctor (draw you a diagram)
- Influences our choice of drug therapy
- Give a clue as to how severe your disease is:
  Both now and in the future
- You need to give accurate information
  In an emergency
  Especially if you see a new doctor

2. IBD affects other parts of the body

- "Extra-intestinal manifestations"
  Problems outside the gut
- 50% of IBD patients
- May be associated with flares of IBD
- Some are 'silent' & picked up on blood tests

1. Liver complications
2. Blood complications

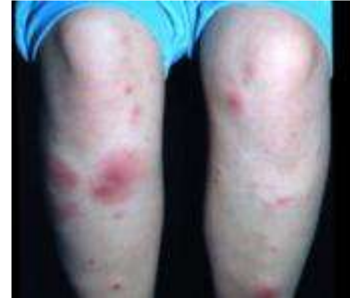
Bloods done regularly even if well and on no drugs

- Others can be picked up by yourselves
- May mean that your bowel is playing up

Problems outside the gut

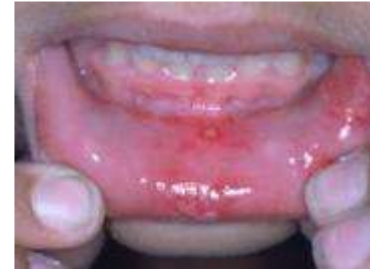
The skin

- Erythema nodosum: common
  Women, Crohn's disease

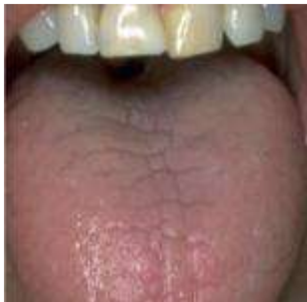


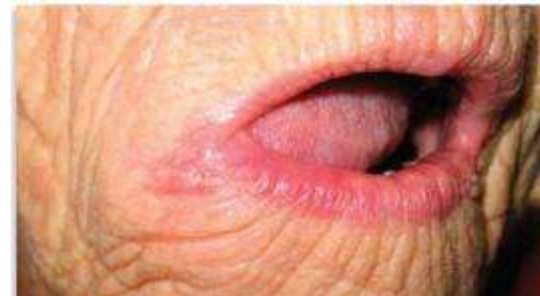
The mouth

- Ulcers, more common with Crohn's

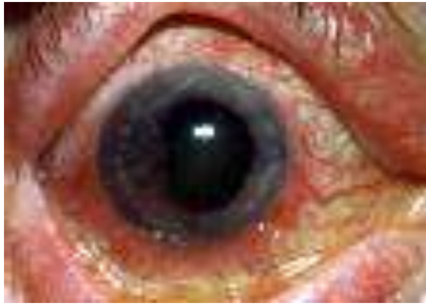


- Iron, folate or Vitamin B12 deficiencies





The eye



uveitis

scleritis

episcleritis

- Painful red eye (often only one eye)
- May cause blindness
- Always see your doctor urgently
- May need referral to an eye specialist

3. You are at risk of osteoporosis

What is osteoporosis

- Low bone density that can lead to fractures, particularly in the hips and spine
- The lower your bone density the greater risk of having a broken bone

Osteopaenia: milder form of osteoporosis

- 30-60% of patients with IBD have it

Osteoporosis

What causes it?

Risk factors:

- A family history
- Excessive alcohol
- Lack of exercise
- Smoking
- Older age (>60 years)
- Women after menopause

IBD patients are at increased risk for osteoporosis

Due to the general risk factors mentioned

And risk factors related to the disease

- Disease-related inflammation
- Medication effects (especially prednisone)
- Decreased calcium and/or vitamin D absorption
- Inactivity during times of bed rest
- Small bowel surgery

How is osteoporosis measured?

- Dual energy x-ray absorptiometry (DEXA) is an x-ray test that your doctor will order initially as a baseline to diagnose any current bone loss
- And then periodically to monitor any changes
- Goal of testing is to identify if you are at risk for osteoporosis before a bone fracture occurs
- Will determine whether you may benefit from medications to help treat or prevent osteoporosis
- Particularly drugs called bisphosphonates

What can you do?

- Eat calcium-rich foods: milk, yogurt, cheese, ice cream, sardines, salmon, broccoli
- Calcium and Vitamin D supplement
- Especially if taking prednisone
- Regular weight bearing exercise – walking
- Stop smoking

4. Smoking is especially bad in Crohn's disease

- Increases the risk for developing Crohn's disease
- It also can trigger flares
- People with Crohn's disease who smoke tend to:

1. Have more recurrences
2. More frequent need for surgery
3. Greater need for immune suppressing drugs

- Crohn's disease patients who quit report fewer flare-ups and reduced need for medications
- Crohn's drugs work better in non-smokers

Smoking and Ulcerative colitis

- In UC (unlike Crohn's) smoking seems protective
- It is unclear why
- UC occurs more in non-smokers & ex-smokers
- Stopping smoking can trigger a flare
- Smoking carries many health risks: any protective effect is outweighed by these
- Tell your doctor before you stop as a nicotine patch can be used for treatment

5. You may be at risk of colon cancer

Some people with large bowel IBD are at risk

- Increased risk in UC: 8 – 10 years after diagnosis
- Especially those with more extensive UC
- Limited UC of the rectum: no increased risk
- CD with inflammation in their colon: also at risk
- Small bowel Crohn's: not at increased risk

What can you do?

- Periodic colonoscopies to check for pre-cancer
- Every 1-2 years, starting at 10 years
- Some medications/vitamins may be protective:

  Mesalazine (Asacol, Pentasa, Salazopyrine)

  Folate (also called folic acid)

6. You need to take your medication regularly

Even when you are feeling well

- Most medications are important to reduce the recurrence of flares
- For biologic medications (like infliximab, adalimumab), it is important to keep taking them to prevent the formation of antibodies against the medication
- Antibodies can lead to allergic reactions and loss of benefit from the drug
- Crohns disease: many people who feel "100% well" still have active disease in the intestine

7. Certain drugs can be risky

Corticosteroids (not anabolic steroids)

- The most commonly used is prednisone
- Cheap, widely available
- Many people self-medicate when sick
- Or use them for prolonged periods

- Important drugs to control a flare short term
- They do not work long term
- Make you feel better but they DO NOT heal
- The longer you take them the less they work

Steroids have lots of side effects

Common side effects:

increased appetite, weight gain, sleep problems (insomnia), mood changes (anxiety, irritability, anger), infections, blurry vision, increased body fat (especially in the abdomen and the face),
swelling of legs and face, slow wound healing, **acne (can be severe),**
dry/thinning skin, easy bruising, increased sweating, **increased blood sugar (especially diabetics)**, increased facial hair, menstrual problems, impotence, or loss of interest in sex. Prednisone can cause decreased growth rate in children., **osteoporosis, cataracts**, glaucoma

Less common but more serious side effects:

dangerously high blood pressure (which may cause severe headache), blurred vision, buzzing in your ears, anxiety, confusion, chest pain, shortness of breath, uneven heartbeats , stretch marks, flushing, low potassium (symptoms include confusion, uneven heart rate, extreme thirst, increased urination, leg discomfort, muscle weakness or limp feeling), pancreatitis (symptoms include severe pain in your upper stomach spreading to your back, nausea and vomiting, fast heart rate), menstrual irregularities,

Corticosteroids

- We try to limit these drugs as much as possible
- And use them for the shortest time possible
- To treat acute attacks only
- The purpose of other IBD drugs like 6-MP, azathioprine, methotrexate, asacol, infliximab, adalimumab is to prevent recurrent steroid use
- Please do not be tempted to take these without discussing it with your IBD doctor

Beware anti-inflammatory drugs

- Non-steroidal anti- inflammatory drugs (NSAIDS)
- Commonly used for pain
- Many can be purchased over the counter
- Ibuprofen, naproxen , diclofenac
- They can precipitate a flare of IBD
- Should be avoided wherever possible
- Panado is the safest pain killer

8. Tiredness may be treatable

- Tiredness or fatigue is very common in IBD
- Even in between flares
- Sometimes due to anaemia which is treatable
- Anaemia is “a low haemoglobin”
  The oxygen carrying part of the blood
- 60 % of patients with IBD have a haemoglobin below normal
- Often due to Iron deficiency from intestinal blood loss or poor absorption
- In small bowel Crohn’s it can also be due to poor absorption of Vitamin B12 or folate

Anaemia and IBD

- Doctors take severe anaemia seriously but may not appreciate the importance of mild anaemia
- Very slight increases in haemoglobin may result in dramatic improvements in energy levels
- Any haemoglobin below normal needs treatment
- Iron in tablet form often does not work
- May need to be given iron via a drip
- All patients with Crohn's of the small bowel need Vitamin B12 shots every 3 months (Vitamin B tablets are not adequate)

9. You should own a thermometer

To measure your temperature when you are sick

If you are on immune suppressing medications:

- Prednisone, azathioprine, 6-mercaptopurine, methotrexate, cyclosporin, tacrolimus,infliximab (Revellex) or adalimumab(Humira)
- You are at high risk of life threatening infections
- It is time to contact your doctor:

  If you have a fever with symptoms like chest pain, cough, shortness of breath, abdominal pain, a sore throat, skin rash,, wound infection

10. Natural is not always safe

Natural remedies: alternative/complementary medicine

- There is no testing, quality control or regulation
- No guarantee they contain what they claim to
- No guarantee that they work
- No guarantee they are safe
- Unlike prescription medications:

  Tested over many years in animals and humans

  Tightly regulated
- May have no biologic activity (harmless but useless)
- Some do have biologic activity and this may be beneficial but can also be dangerous

Supplements and IBD

Herbal supplements:

Echinacea, Cats' Claw, Alfalfa, St. John's Wort:

- Can interact with IBD drugs by interfering with their action or increasing the risk of side effects
- Tell your doctor if you plan on taking these

Fish oil (omega-3 fatty acids):

- May help in CD but unproven in UC
- Few side effects (some develop a fishy odour)
- Expensive
- No guarantee that capsules contain fish oil
- May be cheaper and safer to include fish in diet

Alternative/complementary medicine

Probiotics: also not regulated

- Marketed heavily with little/no medical proof
- Only a few have been rigorously tested
  VSL #3: preventing pouchitis after colectomy
- Generally safe
- Rare cases, probiotics have been dangerous for people who are very sick

No cure at present for IBD

Not everything you read is true

No secret cure for IBD on the Internet

- Enormous amounts of time and money are spent on IBD research
- Any effective treatment, much less a cure, would not remain secret
- There is much to be learned about natural, herbal and alternative therapies in IBD
- At present very little scientific proof