

Health Maintenance & Self Advocacy

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Health Maintenance

- Vitamin D/Calcium
- Vaccines
- Antibiotics
- Routine IBD Maintenance
- Colonoscopies
- Other care providers

- [Health Maintenance Handout](#) (CCFA)
- [Checklist for Care Continuity](#) (Cornerstones)

Vitamin D/Calcium

- Necessary for bone health
- Seattle area—Vitamin D deficiency!
- Corticosteroids can decrease levels of Vitamin D by reducing calcium reabsorption¹
- Vitamin D and Calcium can help control inflammation

¹Pagana, K.D., & Pagana, T.J. (2014). *Mosby's manual of diagnostic and laboratory tests* (5th ed.). St. Louis, MO: Mosby Elsevier.

Vitamin D/Calcium, cont.

- Regular monitoring is important
- Screening in IBD patients with:
 - A history of steroids
 - Known decreased levels of Vitamin D
 - Family history of osteoporosis
 - Personal history of smoking
 - Decreased testosterone levels
 - Males over the age of 65
 - Moderate (or more) intake of alcohol
- Other things that can help bone health:
 - Smoking (stop!)
 - Regular exercise
 - DEXA screening

Vaccines

- Best time to vaccinate—before initiation of treatment!
- Which vaccines are safe for me?
 - *Inactivated* vaccines are safe to receive as both an immunocompromised and non-compromised patient
 - AVOID ACTIVATED vaccines as an immunocompromised patient
- **Activated/Live Vaccines:**
 - Intranasal flu
 - MMR (Measles, Mumps, Rubella)
 - Herpes Zoster (Shingles)
 - Varicella (Chicken Pox)

Vaccines, cont.

- **Generally recommended vaccines for IBD patients:**
 - Hepatitis A and Hepatitis B series
 - Pneumonia vaccines (Pneumovax23 and Prevnar13)
 - HPV series (Human papillomavirus)
 - Meningococcal vaccine for college students (Meningitis)
 - Tdap vaccine (Tetanus, Diphtheria, Pertussis)
 - *ANNUAL* flu vaccine
- Keep track of your vaccine record, especially if you are receiving vaccines from multiple offices/locations!

Antibiotics

- IBD patients have an increased risk of C. Diff
- Use antibiotics *appropriately*
- Ask your provider if there are other interventions that can be used instead of antibiotics
- If you are prone to recurring infections, ask your provider what steps can be taken to avoid infection or early warning signs/treatment options that avoid antibiotics

Routine IBD Maintenance

- Regular lab work
 - Usually every 3-6 months
 - If receiving infusions, can be drawn simultaneously
 - Monitoring inflammatory markers, infection indicators, vitamin levels, and screening for adverse effects of medications
- DEXA Scan
 - Bone density scan
 - Generally every 5 years
 - Ask your Gastroenterologist when you should have this completed

Colonoscopies

- General recommendation: one at year 7-8 post-diagnosis, followed by one every 1-2 years after that.
- It is important to have a screening colonoscopy as recommended, even if you are feeling well and are symptom free!
 - Endoscopic remission
 - Colon cancer screening
 - Evaluation of healing

Other Care Providers

- Primary Care Provider (PCP)
 - Annual health exam—your Gastroenterologist is *not* your primary care provider!
 - Vaccines
 - Pap/Mammogram
 - Females on immunomodulators only (i.e. Azathioprine, 6-MP) have an increased risk of cervical dysplasia, or cell changes
 - Pap is recommended annually for this patient group regardless of prior HPV vaccination history
 - Mental health
 - Up to 20% of patients are affected by depression and/or anxiety

Other Care Providers, cont.

- Dermatologist
 - Annual skin exam
 - Melanoma and Nonmelanoma skin cancer
 - Those at greater risk:
 - Immunomodulator therapy (Azathioprine, 6-MP, Methotrexate)
 - Biologic therapy (Remicade, Humira, Cimzia, Stelara, Entyvio)
 - Decreased levels of Vitamin D

Other Care Providers, cont.

- Ophthalmologist
 - Annual eye exam
 - Uveitis
- Dentist
 - Regular cleanings/exams (every six months)
 - Ulcers, sores, thrush

Self Advocacy

- Knowledge is power
- Provider/patient responsibilities
- Listen to your gut
- Appointment recommendations
- Questions to ask

Knowledge is Power

- Information versus misinformation
- Check your sources when researching on your own
- Ask your provider for information sources
- Utilize the [Crohn's and Colitis Foundation's website!](#)

Provider/Patient Responsibilities

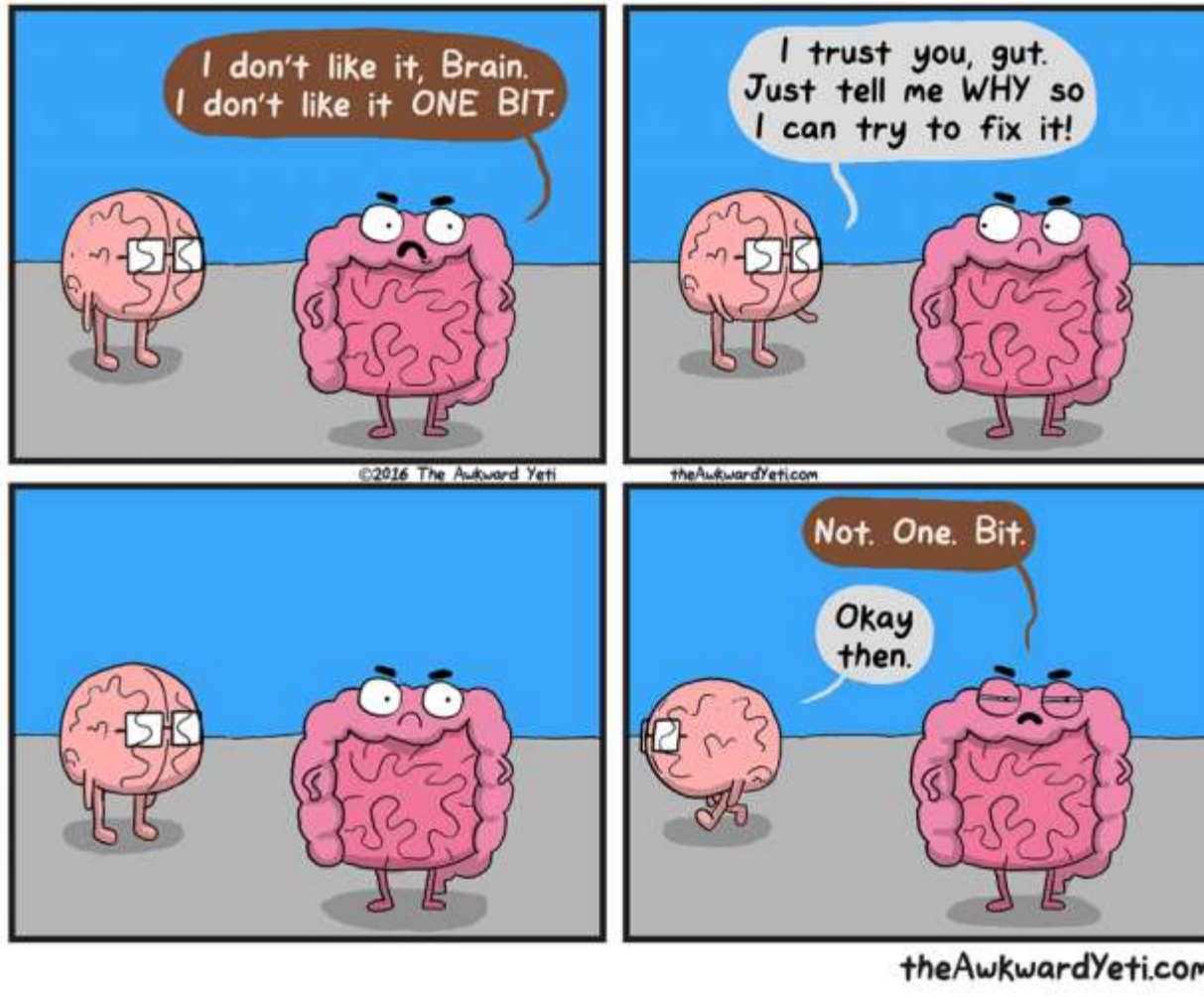
Provider Responsibilities

- Thorough and timely care
- Patient-centered explanations
- Provision of information and choices
- Appropriate diagnostics, treatments, and follow-up care

Patient Responsibilities

- Ask questions, speaking up when something is unclear or uncomfortable
- Compliance with recommendations
- Maintenance care as agreed upon
- Management of prescriptions

LISTEN TO YOUR GUT



Appointment Recommendations

- Arrive to your appointment prepared
 - Insurance cards, photo ID, med lists, copies of previous tests/appointment notes
- Bring a friend/family member with you or ask your provider if you may record your appointment for later reference
- Maintain personal health records—organized!
- Have questions ready in advance

Questions to Ask

- Medications
 - Why am I taking this/what is it for?
 - How long will I be taking this medication?
 - Are there any interactions I need to know about?
 - How should I track this medication?
 - Are there patient assistance programs I can apply for to help cover the cost of my medication?

Questions to Ask, cont.

- Condition(s)
 - How long should I expect to treat this condition for?
 - Aside from taking medications, what else can I do to treat this?
 - Are there other doctors I should see with this diagnosis?
 - What medications/activities/foods/environments should I avoid?
 - What type of ongoing monitoring/evaluation do you recommend?
- [Crohn's Questions](#) and [UC Questions](#)

Questions to Ask, cont.

- Follow Up
 - When should I follow up with you?
 - What medications or therapies should I have tried/completed by the next appointment?
 - Are there labs/imaging/diagnostic tests I should have completed by the next appointment?
 - How far in advance do these need to be done?
 - What should I anticipate at the next appointment?
 - Do you recommend bringing someone with me?

Questions?