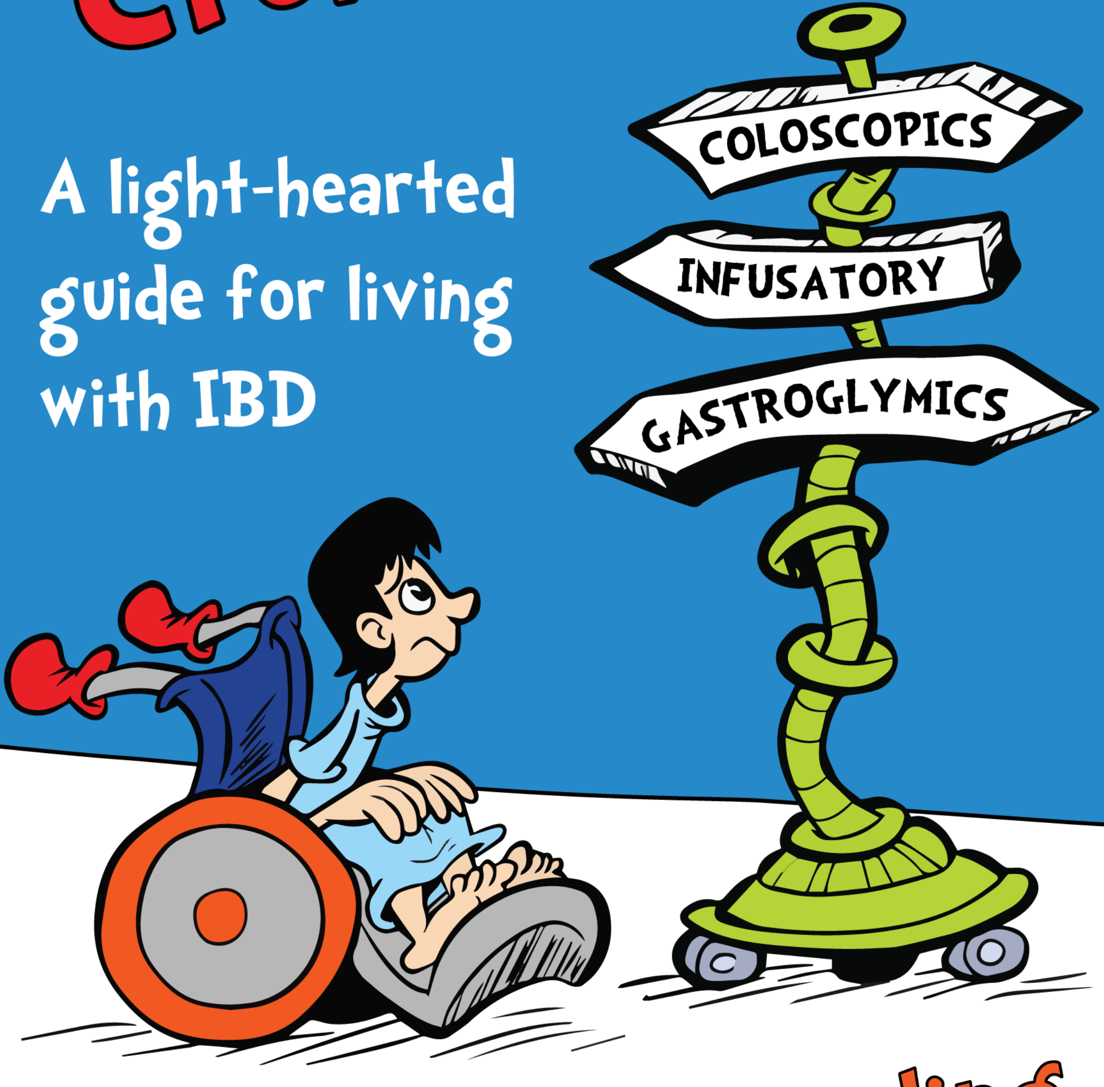
You Only Have Crohn's Once!

A light-hearted guide for living with IBD



By Jeff Geerling

You Only Have Crohn's Once!

A light-hearted guide for living with IBD

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This book is dedicated to my Mom and my Wife, who have both been by my side listening to my antics too many times to count as I woke up from propofol-induced sleep.

Cover illustration by Joey Waggoner.

Contents

Introduction

What a silly title! I hear you say.

And yes, it is a silly title. You can only get Crohn’s or another chronic illness like it once—because it sticks with you the rest of your life!

The title is an homage to a book I’m continually reminded of during my IBD adventures: *You’re Only Old Once!*, by Dr. Seuss.

It’s a strange book, by Seussian standards. While most Dr. Seuss books are targeted at children, this book was aimed squarely at older adults, who can sympathize with the unnamed protagonist as he goes from doctor to doctor, procedure to procedure:

> *He’ll find out by Sniff-Scan the foods you like most.*
> *And when that guy finds out*
> *what you like,*
> *you can bet it*
> *won’t be on your diet.*
> *From here on, forget it!*

But I read the book, cover to cover, when I was ten, before I even knew I had Crohn’s disease! Maybe it was fate.

Before I was diagnosed, I had some stomach pain and bowel problems, so I saw my general doctor. Then a GI specialist. Then a few other doctors. Each doctor ordered tests far more exotic than the last, starting with a colonoscopy and ending with the most embarrassingly intrusive test I’ve ever known, the *barium enema.*

Don’t know what a barium enema is? Don’t worry, you’ll find out in the first chapter!

I started piecing together *this* book when I was still in college. Then I kept writing myself notes as I found my first job, got married, had my first kid, found another job, had three more kids, and went through all these stages of life with Crohn’s punctuating them with hospital visits and test after test.

If you are an IBD patient, a parent or family member of someone with IBD, or even a friend of someone with IBD, I hope this book can help you, wherever you are on your journey.

Be prepared: IBD means poop, bowels, enemas, and all manner of scatological bits and pieces. And this book’s going to deal with *all* of it.

What is IBD?

> *You keep using that word. I do not think it means what you think it means!*
>
> —Inigo Montoya

IBD stands for “Inflammatory Bowel Disease.”

IBD patients have either *Ulcerative Colitis* (“UC”, or sometimes “Colitis”) or *Crohn’s Disease* (“Crohn’s”).

But some people who have Ulcerative Colitis will end up being re-categorized as having Crohn’s, they just don’t know it yet.

Those with IBD can expect to have inflammation in either their colon and rectum (UC), or *anywhere* in their GI tract (Crohn’s), and this inflammation comes and goes as it pleases.

You’re going to hear tons of people saying “oh I know so-and-so and they had that and they were cured when they switched to [*insert diet here*].” Most of the time, these people are well-intentioned but are confusing IBD with IBS.

IBS, or “Irritable Bowel Syndrome”, is *vastly* different than IBD.

The only common thing between the two is the word “bowel”.

You can’t cure an *autoimmune* disease like UC or Crohn’s through diet[1], though your dietary choices can have an impact on the symptoms caused by IBD. This is something people often confuse, but I find it unproductive to try to correct people on the spot.

Rather, I thank them for their concern and tell them how I have been working closely with my doctor to make sure my lifestyle, diet, and medical plans are aligned towards my personal health.

I don’t trust you, where do I go for more information?

Well that’s just fine, this book is not a medical text, and I’m not a doctor.

Lucky for you, there are tons of great resources on the Internet and likely in your own town!

Head to Chapter 9 for advice on how to interact with the IBD community and help make your life—and the lives of other IBD patients—better.

---

[1] There are special diets specifically tuned for IBD, like the Specific Carbohydrate Diet™, the Low-FODMAP diet, or even low-fiber or gluten-free diets which may help *some* patients control flares better. But no diet has been proven to cure IBD, or to prevent flares. Doctors typically recommend working with a nutritionist specializing in IBD to help come up with the ideal diet that serves your nutritional needs without putting you at greater risk due to malnutrition.

1 - The Joy of Crohn's

According to the Crohn's and Colitis Foundation of America, there are 1.6 million Americans with IBD. While that means less than 1% of Americans have either Crohn's or Colitis, that's a pretty big number—and chances are you know someone with IBD, maybe even a close relative!

But due to the fact that Crohn's is usually an invisible illness, many people don't know some of the myriad joys of a typical Crohn's patient's life. This chapter aims to clear that up.

Phobias

Most people I know have one or more of the following phobias:

- Fear of swallowing large pills (pharmacophobia)
- Fear of needles and/or injections (needle phobia)
- Fear of ionizing radiation (radiophobia)
- Fear of germs (mysophobia)
- Fear of confined spaces (claustrophobia)

If you're a Crohn's patient, and have any or all of these phobias, you're in luck! Through the course of diagnostics and treatments, you will be forced to overcome all of them:

- You'll regularly swallow horse-suppository-sized pills multiple times a day

- You'll self-inject numerous drugs (or have them injected via IV)
- You'll receive multiple doses of ionizing radiation and/or other forms of radiation (CT especially, but also X-ray and MR imaging)
- You'll take drugs that effectively shut down your immune system (so maybe the fear of germs won't ever really be overcome…)
- You'll squeeze into tight spaces regularly, like when you have to get your biannual MR enterography. Bonus points for also having to receive an IV (fear of needles) before the procedure!

Often you get a twofer—like swallowing a cup full of large pills before getting an IV, which is all in preparation for a dose of ionizing radiation during a CT scan!

Diagnostics

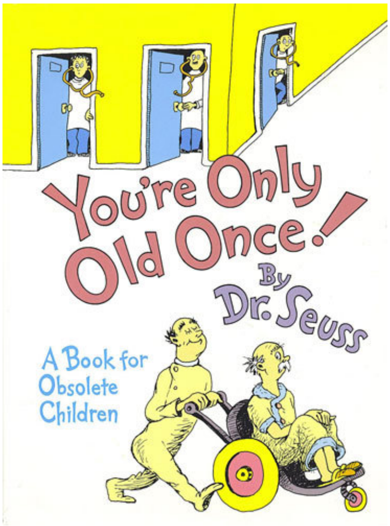
Speaking of CT, MR, X-ray, and such, there are a number of procedures that—unless you have IBD—you might never know about, or expect to undergo until you're an *old person.* Like a procedure where someone sticks a hose in your rectum, pumps you full of goop, makes you flop around like a walrus on an X-ray table while they take pictures, then yanks the hose while you high-tail it to a toilet! (The fancy name for this is a *barium enema.*)

Or the procedure where you have to *drink* a liter of the same goop, wait an hour, then get stuck inside a small tube the width of two basketballs for an hour while a loud machine uses a 30,000 gauss magnet to slice up your body, image-wise, so you can see a glowing image of your squishy intestines. (The fancy name for this is *MR enterography.*)

Or the procedure where you have an IV that looks like something out of a movie, pumping said goop directly into your bloodstream (*in addition to* goop you just drank) while you're stuck inside a machine that spins as fast as your washing machine *around your body* whilst shooting ionizing radiation directly into your body. (The fancy name for this is *CT enterography*.)

Or the procedure where a doctor puts you to sleep then forces a long thick tube camera tube through your rectum, taking a bunch of pictures of your insides, while also cutting out little bits of your intestinal lining for further testing. (The fancy name for this is a *colonoscopy*.)

Honestly, by the second or third time you're run through the gauntlet of tests, you feel like the protagonist in *You're Only Old Once!*, the inspiration behind this book's own theme:



You're Only Old Once!

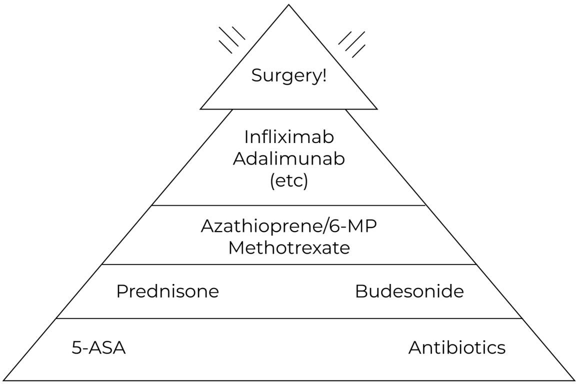
Short synopsis: an old guy gets a zillion exams done, moving from doctor to doctor in a maze-like hospital.

I almost forgot the best part! Most of the above procedures either involve fasting for a number of hours (not the end of the world…), or a full colo-rectal purge—which if you've never done one, feels like this, but coming out of your hind parts:

Geyser eruption (photo by Jacob W. Frank/NPS)

Medicines and Treatments

There is no known cure for Crohn's or Colitis. Someday, there might be one, but until that day comes, you're generally stuck somewhere in this 'pyramid of treatments':

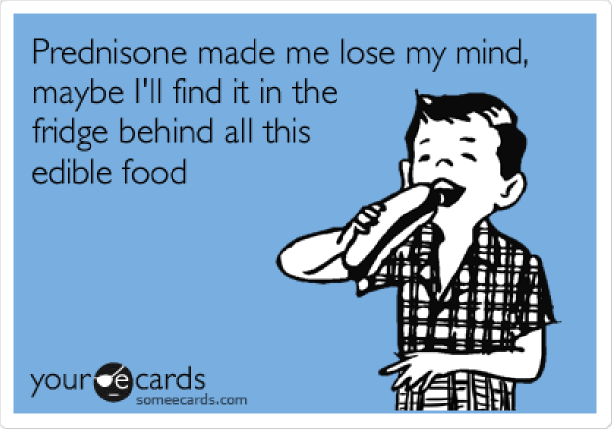


The Crohn's treatment pyramid

You start your way at the bottom, and then climb up. Each new level brings with it an array of new and exotic side effects, as well as exponential increase in price! Also, you usually start with oral medications, then graduate your way up to self-injected medications, suppositories, enemas, and IVs. It's not that fun, to be honest, especially when you realize you're being billed more than your annual salary to sit for hours at a time being injected with a drug that's turning off your immune system (among other things)… and will likely become ineffective at some point (or never help at all—but it takes weeks or months to know!).

Now don't get me wrong—it's a blessing that there are now numerous drugs in every treatment level for Crohn's; in the past, if you developed antibodies to Remicade, you were up a creek and it was time to climp to the top of the pyramid and start cutting out parts of your intestine. Nowadays, there are a half-dozen effective "TNF-blocker" medicines, some better or worse, but all viable options pre-surgery.

In terms of medications for moderate to severe Crohn's, it's not a pretty picture, but it's actually improving over time. And some drugs on the horizon promise to be even easier on our systems, meaning they could help us stay in remission much longer!



Prednisone makes you eat. A lot.

Then there's Prednisone. Everyone patient has a love/hate relationship with it. We'll discuss it later.

Relationships and Family

I have an amazing wife. You have to put up with *a lot* if you are in a dedicated relationship with someone with IBD. Besides the obvious medical exams, potential surgeries and short/long-term disability, monthly medical billing phone calls… there are myriad other lifestyle differences. Like spending hours on the porcelain throne. And laying uncomfortably in bed, on a couch, or on the floor at various times due to crippling stomach pain (usually accompanied by gassiness, which makes it all the more interesting!). And causing vacation or date plans to change (or be somewhat restricted) due to dietary, location, or even bathroom issues!

On top of that, especially for an otherwise-healthy youngish person who has Crohn's, *not* being able to do things like work on a certain home project, do common yard work, gardening, and maintenance, work on cars, etc. can weigh on you. I consider myself a 'provider' for my family… and when I'm not, well, *providing*, that makes me feel bad!

We haven't even started to talk about the impact (superficial or not) of having regular discussions about stool composure, toilet comfort, hemorrhoid care, skin tags, abscesses, fistulas, fissures, and more with those closest to you. I mean, I have kids, so I am used to talking about significant differences in poop. But it's a bit different when you're talking about *your own*!

And for extended family members, who are usually not as attuned to a Crohn's patient's current symptoms and condition, things can be… awkward. Being invited to certain events and not being able to make it because of toilet time, or fatigue—or any number of other reasons—can be tiring, and some people may feel like they're being slighted when it's the third time their invite is declined in a year. I don't blame them, but I *do* know my Crohn's symptoms impact my family relationships.

Work-Life Balance

It's awkward enough for most people to use the restroom *in the long form* at their workplace. Imagine having to do so on a regular basis—sometimes multiple times per day!

I've been blessed to work remotely and in office environments where flexible work hours were allowed, but not everyone has this privilege—This is one area (besides getting Crohn's while very young) where Crohn's disease can be particularly restrictive. There are many occupations that you simply cannot pursue because of the disease. For example, I'm pretty sure the space toilets on the ISS aren't rated for IBD-level fecal escape velocity. There goes my aspiration of being an astronaut!

Mixed blessings

Obviously this chapter is full of tongue-in-cheek statements, but cheer up! There are a few things that Crohn’s patients *can* do that most people cannot:

- Any foods you don’t like? Just tell people you can’t eat them—*because Crohn’s*
- Be billed for hundreds of thousands in medical expenses, year over year (better have good insurance!)
- Listen to friends tell you how you could be cured by eating dirt or sticking other people’s feces into your bowels (*with friends like these, who needs enemas?*)
- Never become obese[2]! If you eat too much, your guts act like a bilge pump and shoves the food right out!
- Quickly locate the most comfortable restroom within one minute’s walk of any urban location on the planet.

Summary

What I’ve said here doesn’t only apply to Crohn’s disease or IBD; there are a range of similar autoimmune diseases and other ailments that are the cause of frequent ‘joy’ in people’s lives. And though there are many negatives mentioned above, there are also great highlights—like working with some great doctors and nurses who want to improve other people’s lives, and realizing how precious time in remission is (when your life is back to normal).

So go give someone with IBD a hug—they might just need one, even if they look like they’re feeling great!

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[2] Unless you’re on a large dose of Prednisone!

2 - At the Hospital

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Sights and Sounds

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The Naked Man

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The Screamer

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The CPAP Neighbor

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Sleep Number from Hell

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The Hundred-channel Cacophony

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There Is No Occlusion

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Nurses

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Doctors

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Food and Drink

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3 - At Home and Elsewhere

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Home Sweet Toilet

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In Public

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The Go Bag

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Social Life

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School

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Work

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Disability

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4 - Colonoscopies

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For starters, the Molotov cocktail

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The morning-of, a.k.a. ‘The Purge, Chapter 2’

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The procedure

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The after-procedure

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The Memory

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Pro Tips for Prep

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5 - Other Common Tests and Minor Procedures

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Blood Tests

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Common blood tests

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Less common blood tests

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Stool Samples

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Capsule endoscopy (pill-oscopy!)

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Flexible Sigmoidoscopy

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Magnetic Resonance Imaging (MRI)

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MR enterography

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Pelvic MRI

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CT Enterography

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Upper endoscopy

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Barium Enema

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6 - Medication

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Corticosteroids

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5-ASAs

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Immunomodulators

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Biologics (the “oo-mabs”)

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Biosimilars

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7 - Surgery

TODO.

8 - Colectomy Surgery, a.k.a. 'The Big One'

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Benefits of a Proctocolectomy and Ostomy

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Downsides of a Proctocolectomy and Ostomy

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Recovery and my new friend, the Stoma

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Bowel Prep

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Recovery in the Hospital

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Managing the pain

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PT, OT, they all stand for 'Torture'

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Things sticking out of your body

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Keeping up the spirits

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Getting 'The Bag'

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Going Home

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9 - Community, Advocacy, and Meetups

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Appendix A - Advice for Parents

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Appendix B - Advice for Friends