

## From Pretending to Truly Being OK: A Journey From Illness to Health With Postinfection Irritable Bowel Syndrome: The Patient's Perspective

Pain is something we all experience. Growing up the oldest in a conservative, protestant, middle class family you had to tolerate pain and learn to deal with it. Getting sick was not an excuse for sympathy or a day off from school. It was almost a badge of honor because you were tough, not weak like others. Maybe that's why, at the age of 13, when it finally came out that I was sexually abused for 4 years by my cousin, I held back communicating my deepest thoughts and feelings about the experience. Rather, I felt the need to express to my mother that I was okay, even though I wasn't. I was a "good girl," but was dying on the inside, and I still had to show I was okay.

So, I stuffed down the emotional pain and moved on to college. I married a great guy, had 2 kids, and with great passion I started a career in health and social justice nonprofits. Although I could help vulnerable, oppressed, and ill people in similar situations, I could not reverse the trauma in my own life. I also managed through more than a dozen surgeries, the care of my son with congenital health issues, and saw family members through attempted suicides, cancer diagnosis, and death. Through it all, I had to be OK.

Ten years ago it all changed. While raising my family and working a full-time, stressful job, I developed food poisoning from a chicken salad sandwich: the fever, abdominal pain, vomiting, and diarrhea were so severe, I almost blacked out. Then the diarrhea turned to blood and I could not leave the toilet. I felt I was dying, barely able to talk and shaking on the cold tiled bathroom floor. In the emergency

room, a CT scan showed my colon was so swollen and inflamed that they transferred me via ambulance to a larger hospital. I spent 3 days receiving antibiotics, IV fluids, and pain meds. The diagnosis was unclear: the hospitalist said *Escherichia coli* gastroenteritis, but the gastroenterologist said possible ulcerative colitis. A colonoscopy was recommended, but it couldn't be completed until I was better.

One month later, the pain and bloating with diarrhea continued so I went to a GI specialist hoping he could help. Sadly, that was not my experience (Figure 1).

Dr.: Hi, I'm Dr. Blah Blah. (limp fish handshake) So, why are you here? (Looking at my chart and avoiding eye contact.)

Me: (Sitting in a gown, cold from waiting 30 minutes in the examination room.) Hi, Doctor. Well, I was in the

hospital for a bad case of *E coli*. They recommended I follow-up with you to have a colonoscopy for a diagnosis and treatment. I still have pain and loose stools; I didn't know if that is normal or not.

Dr.: (looking at the computer) Uh-huh, okay. (Silence.) Well, you're too young for colon cancer so it's probably nothing serious. I'll do one if you want. (Turns to me.) Try some probiotics for the pain, and Kaopectate for loose stools. I will have the nurse set up the colonoscopy.

I couldn't believe it. "Really?" I thought. "You'll do a colonoscopy if I want one? Who WANTS a colonoscopy?! Shouldn't you make that call?" "Did you read my hospital record to see about possible colitis?" But I just sat there startled and wondered why I was in a gown if he didn't even do a physical exam.



**Figure 1.** There is a lack of engagement as was demonstrated at the beginning of Johannah's story. The doctor is avoiding eye contact while looking at the medical record, and is turned away from the patient. He waves his hand in a way that dismisses the patient. The patient in turn is looking down with slumped shoulders and with crossed arms and legs displaying passivity and nonacceptance.

## COMMENTARY

119 Me: Uh, okay, so, that's it?  
120 Dr.: (Already closing the door on  
121 his way out.)

122 I had the colonoscopy but I was  
123 dreading the follow-up appointment  
124 because our last encounter had gone  
125 so poorly. Nevertheless, I wanted to  
126 get to the bottom of this once and for  
127 all.

128 Dr.: (Talking as he entered the  
129 room, head down reading my chart and  
130 sitting on his rolling doctor stool.) So,  
131 everything looked fine. I took out 2  
132 small polyps. There was very mild  
133 inflammation but nothing like UC or  
134 Crohn's and certainly no cancer.  
135 (Looks up.) So, good news all around.

136 Me: Well, that's good. So why am I  
137 still having pain and loose bowels? Will  
138 that resolve on its own? Is it left over  
139 from the infection?

140 Dr.: (Looking at the computer and  
141 typing.) Probably. Don't worry about it.  
142 Stress causes this too, especially in  
143 women. You'll be fine. I won't need to  
144 see you again unless something  
145 changes. Just follow-up with your pri-  
146 mary care doc if needed. (Gets up and  
147 heads to the door.) Take care.

148 I couldn't believe that he dismissed  
149 my questions so quickly. His words  
150 stung like a slap on the face. He didn't  
151 need to see me when I still felt so bad  
152 with these symptoms!? He had no inter-  
153 est in or understanding of what was  
154 happening and what it meant to me. He  
155 was really saying, "It's not that serious  
156 to me, so I don't want to spend any  
157 more time dealing with you." I was  
158 angry, hurt and frustrated. As a young  
159 girl, I was taught not to question au-  
160 thority and even as a grown, educated  
161 woman, I still resort to this thinking.  
162 Clearly, if a specialist did not think my  
163 symptoms were an issue, then maybe  
164 they really weren't. Maybe I was being  
165 a baby. My family's words echoed:  
166 "Suck it up, you're fine, stop making a  
167 big deal about it." So I thought, "Okay,  
168 I'll just deal with it."

169 Over the next several years, I  
170 continued with the abdominal pain and  
171 diarrhea, but it intensified and became  
172 almost constant, depending on time of  
173 day and what I had eaten. I thought it  
174 was worse when I ate dairy or meat, so  
175 I eliminated them and lots of other  
176 foods from my diet: broccoli, aspar-  
177 agus, dairy, beef, and pork. I tried

heating pads, sleeping with a pillow  
under my rib cage, Gas-Ex pills, Imo-  
dium, and upwards of 12 probiotic  
pills a day.

The effects on my family were  
profound. I had to cancel on friends  
and family. I wasn't well, and didn't  
know if I could get to a bathroom  
quickly enough. I missed family soccer,  
football games, and concerts. Week-  
ends were spent with me in bed and  
my husband and kids playing games or  
watching movies. My marriage was  
affected; who wants to be intimate  
when dealing with constant pain,  
restricted diets, and unpredictable  
bowel habits? So, I relented and saw  
three other doctors, who after review-  
ing my chart told me that I should eat  
more yogurt (but I gave up dairy),  
drink more water (why didn't I think  
of that?!), and try yoga (Is there a  
bathroom nearby?). Maybe I should  
hike or swim to reduce stress (if it  
were just that easy).

I had given up hope that a gastro-  
enterologist was going to help me, so I  
saw an internist. This was my worst  
interaction.

Dr.: "Could you be exaggerating the  
pain a bit? From what I see in your  
chart, there is no structural cause for  
your symptoms. If it were as bad as  
you say, how can you hold a job or  
raise a family? Women can get hys-  
terical and exaggerate pain, especially  
at certain times of the month. Maybe  
it's not as bad as you say?"

Stunned, pinching my arm to keep  
from crying and embarrassing myself, I  
felt the need to justify myself and my  
symptoms. My inner voice screamed:  
"Why are you letting someone speak to  
you like this, make you feel insignifi-  
cant and unworthy, and even call you a  
liar?" Yet the little girl in me needed to  
prove to him that I was okay despite  
my symptoms, to prove the legitimacy  
of my pain and its effect on my life. I  
told him I worked every day, even  
though I was hurting with a heating  
pad at my desk, how I cared for my  
family even when repeatedly going to  
the bathroom, and how I served on 8  
different nonprofit committees and  
boards in town while eating Imodium  
like candy.

I began my master's degree pro-  
gram and worked full time. My pain

was now wide-spread also affecting my  
hands and feet as well. I was  
constantly tired and developed fogg-  
iness and forgetfulness. The doctors  
said I had fibromyalgia and gave me  
gabapentin for the pain and for sleep.  
Is fibromyalgia a real diagnosis? Did it  
come from the chicken salad sandwich  
and relate at all to the GI pain and  
symptoms? How could my health have  
declined so badly? Did I do something  
to cause this? I felt at the end of my  
rope, hopeless and lost.

Over time I missed more work. I  
even left an awards dinner early,  
where I was being honored as a top  
Professional Under 40. Going home, I  
sat in the car with tears in my eyes,  
frustrated and tired at the course my  
health had taken all these years.

I wanted to scream: I AM IN PAIN.  
WHY CAN'T SOMEONE HELP ME! I felt  
the diagnosis of fibromyalgia, the pro-  
biotics, yogurt, water, and yoga were  
all hodge-podge recommendations  
given as a last resort. I couldn't bear to  
hear that I had "mystery" symptoms or  
that I was "exaggerating." I believed  
my doctors would say, "We don't know  
what else to tell you and don't see any  
legitimate reason for your symptoms,  
so this is the best we can do. We don't  
want to really understand how this is  
affecting your life. So, please, stop  
coming; figure it out on your own."  
My medical chart must have said:  
"She is exaggerating the pain and  
diarrhea, and probably won't accept  
that this is stress. Smile, nod, and send  
her on her way with a new probiotic  
to try."

So, I stopped seeing doctors and  
tried to cope and adapt my life to this  
"new normal." I got my MEd with  
honors, poured into my work, and did  
the best I could to manage these  
symptoms. Then my husband got a job  
transfer across the country and my life  
changed. I started a new job and heard  
there was a GI specialist who might be  
able to help me. I was skeptical, but  
after stumbling back to the table from  
the bathroom for the third time while  
out for dinner, my husband convinced  
me to see him.

Dr.: (Looking directly at me with a  
smile) Hello, I am Dr. Blah Blah.  
Thanks for coming in? How are you  
and how can I help?

178  
179  
180  
181  
182  
183  
184  
185  
186  
187  
188  
189  
190  
191  
192  
193  
194  
195  
196  
197  
198  
199  
200  
201  
202  
203  
204  
205  
206  
207  
208  
209  
210  
211  
212  
213  
214  
215  
216  
217  
218  
219  
220  
221  
222  
223  
224  
225  
226  
227  
228  
229  
230  
231  
232  
233  
234  
235  
236

237 Okay, right away, I thought, "Why is  
238 he looking at me instead of the  
239 computer?!"

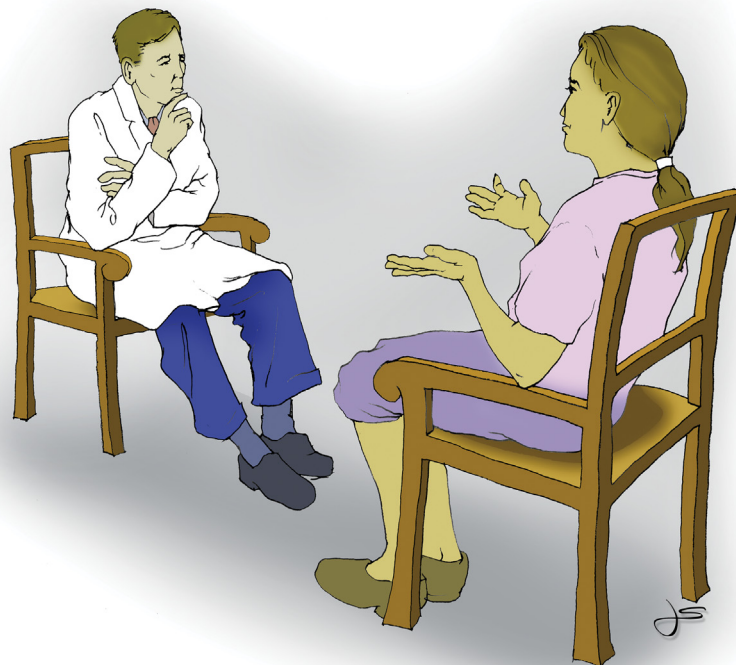
240 Me: Uh, well, I have some stomach  
241 issues and thought maybe you could  
242 help.

243 Dr.: Okay, glad to try to help.  
244 (Smile.) Tell me about your symptoms.

245 This dialogue went on for about an  
246 hour (Figure 2). With his encourage-  
247 ment, I discussed my symptoms, my  
248 feelings about them, and their effect on  
249 my family as well. He asked follow-up  
250 questions, expressed concern and sup-  
251 port for my feelings and the impact my  
252 symptoms had on my personal life. I was  
253 excited. I thought to myself, "Why had I  
254 never experienced this dialogue with a  
255 doctor before?"

256 Suddenly, a glimmer of hope began  
257 in my soul. Even if he couldn't  
258 completely help me, I knew he cared  
259 and was going to try. I felt validated  
260 and supported, and was overwhelmed.  
261 When he told me that postinfection  
262 irritable bowel syndrome (IBS) caused  
263 my symptoms and that they could be  
264 treated, I was relieved. Through his  
265 explanations and diagrams I learned  
266 that post infection IBS can occur when  
267 there is a gastrointestinal infection  
268 associated with stress. Strangely, this  
269 was exciting to hear, because it was so  
270 validating. I also learned how my  
271 earlier experiences triggered my help-  
272 lessness with new challenges like this  
273 illness. Then we talked through treat-  
274 ment options. He explained why he  
275 would like to use an antibiotic for the  
276 IBS and an antidepressant to treat the  
277 brain's poor regulation of the pain.  
278 Then he asked how I felt about the  
279 plan and we discussed the risks and  
280 benefits. I agreed willingly, because I  
281 was now part of the process of my  
282 care. Although recovery could take  
283 time, he assured me that he was in it  
284 for the long term and I knew he  
285 wouldn't abandon me. They say that,  
286 when one is heard, they feel valued  
287 and loved. This was certainly the case  
288 for me, especially after so many years  
289 of being ignored and dismissed.

290 Today, my GI pains are resolved. I  
291 eat normally without restriction. I  
292 rarely have nausea or bloating, and my  
293 widespread pain and fatigue are a  
294 memory. How did this happen? Was it  
295 the pills or a placebo effect? Was it the



**Figure 2.** As occurred later in Johannah's story, the doctor is facing the patient and making good eye contact. The finger on his chin indicates both receptive thinking and active engagement. To the patient, this communicates interest and acceptance by the doctor of what she is saying. The reinforces the patient to say more as she looks back at him with an open posture and active gesturing.

296 doctor or just the passage of time? Or  
297 was it me?

298 Here's what I now know: The  
299 patient-doctor relationship is complex  
300 and challenging. Chronic illness and

301 pain can make you feel like you are  
302 spiraling out of control, especially  
303 when you falsely assume there isn't  
304 any "real" cause for it and seemingly  
305 no way to treat it. Patients see a doctor

**Table 1.** ■■■■

Patients Should Know	Doctors Should Know
You and your health are worth fighting for, no matter what. You can demand to be treated with dignity and respect. You have a right to share your personal thoughts and feelings about your care You have a right to ask questions and receive visual aids to understand your diagnosis and treatment. You have a right to be heard.	Patients need to feel that you care about them as a person and not feel judged. Patients need to feel respected to share personal details that will assist you in their care. Patients need to feel that their doctor will be receptive to their thoughts and feelings
You have the right to engage with your doctor as a partner	Patients need to understand the diagnosis and treatment plan to participate and feel like they have a say in the process. Patients are not impressed with ego and prestige; they want you to be humane and to care about the impact of the illness on their life.
You can refuse treatment or seek another opinion if your needs are not being met.	Patients are okay with "I don't know" as long as you continue to work with them, or guide them to someone who will. Patients need to know that you are not going to abandon them.

print & web 4C/FPO

296  
297  
298  
299  
300  
301  
302  
303  
304  
305  
306  
307  
308  
309  
310  
311  
312  
313  
314  
315  
316  
317  
318  
319  
320  
321  
322  
323  
324  
325  
326  
327  
328  
329  
330  
331  
332  
333  
334  
335  
336  
337  
338  
339  
340  
341  
342  
343  
344  
345  
346  
347  
348  
349  
350  
351  
352  
353  
354

## COMMENTARY

hoping to regain control through treatment, but know they may not have a “quick fix.” What patients want is honest dialogue, to be heard and understood and not dismissed. They don’t mind if a doctor says they aren’t sure what’s going on, as long as they are committed to finding out, and won’t abandon them. My care changed when I was able to honestly share my symptoms, thoughts, and feelings with my doctor and know that he would listen and try to help; that made me feel validated and empowered. Even on days when I don’t feel 100%, I know that together, my doctor and I will come up with a plan to address my symptoms. Knowing that he wants my

input and lets me know I can trust him makes me compliant with the treatments that we decide on together. Also, when a patient truly trusts their doctor, they feel safe to share other personal aspects of their health and experiences that might relate to their current condition and open more doors to further treatment options.

My interaction with my doctor helped me to find my voice and to advocate for myself. Now I expect the same in the future, no matter what doctor I see. I also learned through this ordeal my role in the negative interactions with doctors. The difficulties with the doctors reverberated and amplified the feelings of helplessness,

poor control, and anger that came from my childhood traumas. So, although I ferociously fought for my children, family, and friends, when the doctors came at me I shrank. No one should be given the power to take my health, my light, or my truth. I now feel a new sense of empowerment, as a patient and as a woman. For the first time, I can say, yes, I am okay. Really, truly, okay.

*JOHANNAH RUDDY*

Rome Foundation  
Raleigh, North Carolina

© 2018 by the AGA Institute  
0016-5085/\$36.00

<https://doi.org/10.1053/j.gastro.2018.11.003>

416  
417  
418  
419  
420  
421  
422  
423  
424  
425  
426  
427  
428  
429  
430  
431  
432  
433  
434  
435  
436  
437  
438  
439  
440  
441  
442  
443  
444  
445  
446  
447  
448  
449  
450  
451  
452  
453  
454  
455  
456  
457  
458  
459  
460  
461  
462  
463  
464  
465  
466  
467  
468  
469  
470  
471  
472  
473  
474  
475  
476

Q3

Q4

Q1