

About IBD Podcast Episode 104

Lt Colonel Joshua Nelson - Living With Ulcerative Colitis as an Air Force Pilot

Did you know that being diagnosed with ulcerative colitis or Crohn's disease is a disqualifying condition to serve in the United States military? However, it seems that it's not always an automatic reason for discharge. Lt Colonel Joshua Nelson was diagnosed with ulcerative colitis and needed to have ileostomy surgery. It cast into question his future as a pilot in the Air Force. Learn his story of how he worked with his medical team in order to keep doing the job he loves, his advice for others like him, and tips on flying that any ostomate can use.

Concepts discussed on this episode include:

- [Types of Ulcerative Colitis \(UC\)](#)
- [Pseudopolyps in IBD](#)
- [Cryptosporidium Infection](#)
- [How to Prepare Yourself for Ileostomy Surgery](#)
- [Ulcerative Colitis Surgery](#)
- [Do Men Become Impotent After Ostomy Surgery?](#)

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[MUSIC: About IBD Theme]

Amber Tresca 0:04

I'm Amber Tresca. And this is about IBD. It's my mission to educate people living with Crohn's disease or ulcerative colitis, about their disease, and to bring awareness to the patient journey.

Amber Tresca 0:15

Welcome to Episode 104.

Amber Tresca 0:18

The idea of serving in the military with IBD has come up over the years in my work as an advocate and educator. During my research, I discovered that IBD was usually considered a disqualifying condition. In particular, a diagnosis could prevent a person from enlisting in the military. And in fact, I've talked with a few people who served in the military and were discharged after they were diagnosed with a form of IBD.

Amber Tresca 0:43

That's why when I saw Lieutenant Colonel Joshua Nelson in the national news, I was immediately interested and I wanted to bring his story to the patient community. He has a thriving career in the Air Force, but he also has ulcerative colitis. His disease was severe, and he had surgery to place an ileostomy from Minnesota. Let's welcome Lieutenant Colonel Joshua Nelson.

Amber Tresca 1:09

Lieutenant Colonel Nelson began his Air Force career shortly after graduating high school. He didn't have a concrete plan. But he knew he had a passion for aviation.

Lt Col Joshua Nelson 1:20

I've always had a fascination for it. And I didn't care at the time, if I was working on them or flying them. I mean, honestly, there was always that ambition to fly them. And really what it took was it was my sophomore year in high school, a family friend and his family took me on a trip to Florida. And just flying those first time flew like this is this is the coolest thing in the world.

Lt Col Joshua Nelson 1:40

At the time, the only way I thought you could fly for the military was going to one of the academies. But obviously I joined the military for the college benefits. One of the job opportunities was an aerospace maintenance technician. I said, Well, what's that, like, were you kind of like a crew chief oversee 130, where you're kind of like the go to guy in charge of the maintenance on the airplane? Well, that's really neat.

Lt Col Joshua Nelson 2:00

So I graduated high school in 2000. I went to boot camp, and later 2000, I think was November of 2000. Graduated boot camp, the end of December of 2000. I went to technical training for maintenance. And I got back from there in May of 2001. I did one month of training at Little Rock. And that was really fun. So I got back in about June, which allowed me to go to college, the fall of 2001. And it was honestly, one of the great perks of the job was if the airplane went off station somewhere, you could go with it. You're that guy who would fuel it, you would clean it or you would perform maintenance on it when the airplane was on the road. And so I remember being on one of the out of state, the TDY what we call temporary duty locations, and one of the pilots has came up to me said, "Well, what are you doing in college," and I was just living doing what anyone does in college, you know, going to school, having fun, meeting people. And he just said, you know, we can hire you when you graduate? Come again. Is this possible?

Lt Col Joshua Nelson 2:59

So literally it was. So I took a couple more tests, and I graduated college in 2005. I was hired that same year. And then in 2006, I went to officer training school. And that was in Montgomery, Alabama, where I earned my commission as a Second Lieutenant. And following that I went to one year of flight school at Lackland Air Force Base from 2006 to 2007. I was a

classical 714 at Laughlin. And that's where you earn your wings, you become a pilot. Following that course you go to, I knew I was going to fly the C 130.

Lt Col Joshua Nelson 3:32

So I went to Little Rock, Arkansas for seven months for pilot initial qualification. And that's really teach you to pretty much become a co pilot. And that's every capability that airplane has. Once you graduate there. I came back to Minneapolis, Minnesota where we're located. And I've been doing that ever since. I've been to aircraft commander school. I've been to instructor school. I am the Chief of standardizations and evaluations within the organization. And I've been a full timer there for about the last eight years.

Lt Col Joshua Nelson 4:03

And really what that means is for us as reservists is I'm what's called a dual status technician. So during the week, I'm like a federal employee, but then on the weekends or anytime I do military duty, I can easily swap over to that role. So I came back from school as a second lieutenant and now I'm a lieutenant colonel. I've served for over 20 years. I've done five deployments in my career on the airplane to so you know areas such as Southwest Asia, I've been all over the world. I have over 4000 hours in that airplane.

Amber Tresca 4:35

In 2017. Josh developed Cryptosporidiosis, which is an infection from a parasite called *Cryptosporidium*. *Cryptosporidium* causes 1000s of infections in the United States each year, but Josh had never experienced anything like it before. That's when his IBD journey began.

Lt Col Joshua Nelson 4:55

I have no family history of this whatsoever. You know, one of our, you know our aircraft were getting modifications done and that was down in Mississippi. So southern US obviously, when I returned, I somehow contracted *Cryptosporidium*, which is a parasite infection of the GI tract. And I started to have just uncontrollable diarrhea is what it was. So I do what everybody does, they show up at their local healthcare practitioner and just say, I have diarrhea and I can't control it. And they started to prescribe me just basic medications to try to, I had to bring in stool samples, then I started getting prescribed some medications for that to hopefully eliminate the *Cryptosporidium* and let it flush through my body.

Lt Col Joshua Nelson 5:35

But while that was taking place, I just was not getting any better. The diarrhea started, and then I started to notice the blood in my stool as well. I ended up getting hospitalized pretty much throughout in November of 2017. And I had an emergency colonoscopy done the next day because I had a CT scan that showed massive inflammation in my large intestine. And so they're like, this isn't good, we need to get this looked at. And they couldn't tell me why or where this was coming from. Because the theory the medication I was on for *Cryptosporidium* was supposed to take care of all that in that timeframe.

Lt Col Joshua Nelson 6:09

So I had the emergency colonoscopy done the following morning. And a couple of days later, once I was discharged, I got a phone call from one of the doctors said you've been diagnosed with ulcerative colitis. And this was November 2017. I remember thinking on the phone, what in the world is ulcerative colitis? Somehow, my body's attacking the inner lining of my large intestine. It's like — are you kidding me?

Amber Tresca 6:34

The doctors prescribed mesalamine for the ulcerative colitis. Josh did improve. And a few months later, he had a second colonoscopy to see how he was responding. His colon looked better. He no longer had any pain. And he was spending less time in the bathroom. There was something else that was concerning though. His colon had pseudo polyps, which are not true polyps, but are scar tissue that occurs after inflammation has healed over. But this wasn't his biggest worry at the time.

Lt Col Joshua Nelson 7:05

The problem with my job as an Air Force pilot is once the diagnosis landed with ulcerative colitis, that is a disqualifying condition. For me as an Air Force pilot, it's also a disqualifying condition for any member of the military because obviously we have certain requirements we need to maintain in order to do our job. So that was part one of the battle is how do I overcome and keep my job and stay in the military with ulcerative colitis, and the goal would be started medication treatment, and as long as you're stable with clean labs, clean biopsies, clean scopes, and the medication is working for you. You should be okay.

Lt Col Joshua Nelson 7:46

Unfortunately, it didn't happen. Pretty much I think it started in the spring/summer. And I remember going to the bathroom. And I noticed blood. And I remember the GI people telling me that you know, hey, if you see blood, we need to know about it ASAP, because that's usually not a good thing. Right? And so I called them up and they immediately put me on prednisone. And the problem with prednisone with me is I did okay with it around the 40 milligrams 35 to 30. Now, as you begin that taper, I could never get below 20. And so the frustrating piece for me as a as an individual with ulcerative colitis was truly finding out how difficult it was to make an appointment with a GI person. When you have blood happening in your stool. I remember calling them up. They're like, well, the earliest we could probably get you in is four to six weeks. I'm like, Are you kidding me?

Lt Col Joshua Nelson 8:37

I ended up getting hospitalized again. Because the goal of being hospitalized and I would drive myself in I'm getting uncontrollable bowel movements. Again, uncontrollable bleeding, I'm in pain again. during that timeframe, I'd also went from the modality products to the biologics. They put me on Humira. I remember every single time I started a new treatment was almost that glimmer of hope, will this work? Will I be able to get my job back and continue to fly the airplane that I love to do with this treatment because every time I had a like a hiccup, I'm not showing that's the ability that they're looking for when it comes to the medication that you are on.

Lt Col Joshua Nelson 9:17

And so that hospitalization that I was at was towards the end of September of 2018. So I haven't even been diagnosed for a year yet and I'm already having some massive complications. There were times where I was curled up into the ball, into a ball in the basement, multiple bowel movements, and I knew where every single bathroom was from my house to where I work.

[MUSIC: About IBD Piano]**Amber Tresca 9:51**

After talking it over with his wife, Josh contacted the Mayo Clinic and was able to see the specialists there. They confirmed the diagnosis and added azathioprine to his medications. Because the University of Minnesota was closer, they recommended that he seek care there if he continued to get worse.

Lt Col Joshua Nelson 10:11

And that was the first time when I went to Mayo was the first time I heard of an inflammatory bowel disease specialist. So when I made it home from the Mayo Clinic and bought the middle of October, I just was not getting any better. Again, I'm in a ball downstairs, multiple...I'm not even sleeping in the same bed as my wife. Because I'm out of the bed so many times she has a full time job, we have two little girls.

Lt Col Joshua Nelson 10:31

So I remember calling my dad one morning I just said, dragged me down to the U of M. I mean, I'm, I'm normally 190 pounds 5'10' I'm getting...I'm not eating. So whatever is coming out of me is everything. That's mucus, abscess, that's just destroying my colon. And it's becoming 18 to 20 bowel movements a day. So he drives me on down. And the great thing about the University of Minnesota Medical Center I love is once they finally admit you, you meet everybody, your floor care team, the inflammatory bowel disease specialists who I finally are meeting with and the colorectal team. You know, they kind of give you everything when you first get on in there. So at this point, they're saying Yep, Humira is not working, for your body's not reacting to Humira. Now we're going to try Remicade.

Amber Tresca 11:17

But Remicade didn't work, either. Josh was running out of options. He was hospitalized for close to a month, he had several more colonoscopies. And it turned out that none of the medications were working to treat the ulcerative colitis. He was in constant pain now, and was becoming malnourished. He found himself in the bathroom every 30 minutes, and at times, he lost control of his bowels. That's when his medical team approached him about making a new plan.

Lt Col Joshua Nelson 11:47

They determined that it was in my best interest to have my colon removed. And I remember about a day before I had the surgery, the floor care team comes in and they kind of sit you down like how are you doing psychologically? You know, are you okay? With the decision being done and I'm like, I don't care what it is that you do I want this disease done with. Once the decision was made to have my colon removed, now we can. And I was so malnourished, at the same point, it was getting frustrating, because during that whole time, I realized what the disease did to people, and made you a prisoner in your own home and made you a prisoner to the proximity of a toilet.

Lt Col Joshua Nelson 12:25

Anywhere I went, it wasn't "am I going to have fun here?" "Where's the bathroom? In case I need to go?" It took your qual...it takes your quality of life away. I mean, I'm not even worried about my job. At this point. I just want to get better. I want my life back. And I remember meeting my surgeon when I first got there, and I remember him telling me like I have a feeling I'm going to see you later. I was like, Well, what is that? You know, did he just know something I didn't? And at the time where if I'm just not respond to medications, sooner or later, I'll end up under his care and have my colon removed.

Lt Col Joshua Nelson 12:56

So the day comes where I have my first surgery. And that's obviously the one where they took he took about 75% of my colon out. And my mom and my wife are down there well for surgery. And when he came on out to meet with my wife and my mother, he's like we made the right decision. Like his colon was destroyed. It was abscess, it was falsified. It was a deep purple. It was so inflamed. He's like, I don't think, we, I don't think if it wasn't for the surgery, I do not believe he would have overcome this.

Lt Col Joshua Nelson 13:29

But I do remember beforehand that for surgery, he said you will feel better. And I didn't know what he meant at that time. But he was right. I mean, the next day the pain was gone. And it was at that time that I said to myself never again. And people asked me what does that mean? I said Never again, never again will I allow myself to become that ill. That malnourished, that unhealthy. And that triggered something in my brain. And that's kind of something I've always lived to now is keep your head down, keep moving forward, one foot in front of the other no matter what don't ever quit.

Lt Col Joshua Nelson 14:01

And one of the follow up appointments that I had with them, you know where they give you that time in between both surgeries to figure out if you want the internal pouching system or if you want to have your ileostomy be permanent. And all it took for me was the disease can still attack that j-pouch and take it out. I want nothing to do with this. So the final surgery was February of 2019. That made my ileostomy permanent and I haven't looked back. I'm someone who lives with no medications, no restrictions, no special diets, and I do not care that I have an ileostomy hanging off my abdomen. I wear it proudly it gave me my life back and gave me that second chance.

[MUSIC: About IBD Piano]

Amber Tresca 14:52

After his ileostomy Josh was getting stronger and returning to health. The next step was to get back to his job as a pilot in the Air Force.

Lt Col Joshua Nelson 15:03

But that was approved, to return to flying status, in November of 2019. So it had been about two years since I was initially diagnosed to get back into the airplane, there's no greater honor or responsibility to begin being given the hands to the keys of the C 130. And having leadership, say, go execute your job, going through my medical process. That is why I fought so hard, because this is something I worked so hard to get to. I love to do it.

Lt Col Joshua Nelson 15:34

And one of the greatest things I think I came out with was my relationship with my surgeon, he knew what I did, and that it even applied to the civilian medical staff is I was fully open and honest with them what I did and how important was for me to try to get back to that. So doing well on the fitness exam, proving and showing to them that I could still do my job, even though I have an ileostomy. You know, taking care of myself mentally, emotionally, psychologically, everything to show that I went through this transition, but I do believe I came out better in the end. My surgeon was instrumental, because the military medical staff does not have the expertise that the civilian industry does.

Lt Col Joshua Nelson 16:19

But there were concerns such as, what if the bag explodes and flames? What happens if you operate dark out conditions? What happens if you operate high altitude on pressurized conditions? What about high G environments? What about? I think the verbiage they use was not compatible with military aviation. What does that mean? No one could tell me. So it was overcoming that I mean, we have, my case went up to the headquarters Air Force Surgeon General, the highest it can go.

Lt Col Joshua Nelson 16:53

And I remember seeing something on a piece of paper. That individual said, Thank you for your recommendation. We find this medically acceptable, stamped approved. And when I was told, I was completely prepared to accept: you're not coming back, you're going to be medically retired, I have over 20 years of service. And so we were prepared for that. And to have that phone call and say congratulations. It's like — we, we did it.

Lt Col Joshua Nelson 17:21

And I just fell off. I mean, my squad members, I cried. Because the amount of stress that came off of my shoulders, knowing that somebody believed in me, I'm a piece of paper. No one has ever seen me. No one has ever met me face to face. I'm a piece of paper. So somewhere on that piece of paper, we did a good enough job for someone to go, maybe this is okay. I cried. I

broke down. I'm pretty sure one of my bosses pulled out the scotch. And we had a shot or two. Just because that's how many people were rooting for me.

Lt Col Joshua Nelson 17:56

And so far, we've been pretty successful. I've not run into one complication at all. Never had an issue in the airplane with an ileostomy. Everyone at work, gives me crap, no pun intended, right? You know, we have a bathroom in the back. And, you know, it's not as glamorous as an airline bathroom. But you know, dang it, there's a chemical toilet. There's a curtain around there. And I've even experimented with it. I've walked back there and done my stuff. And I'm in and out of there in like three minutes, no one would even know what I'm doing.

Amber Tresca 18:24

One thing that new ostomates have questions about is flying and how it will affect their appliance. Josh and his team had those same concerns. But flying a military aircraft subjects him to bigger extremes in altitude and pressure. He explains how he manages while working and gives advice about flying after having ostomy surgery.

Lt Col Joshua Nelson 18:45

So in my first year of being allowed to return to service, the goal was to kind of exercise the envelope of the ileostomy — every concern that they had. So I did a cross cutting or an off station trainer, a TDY, to Yuma, Arizona, we were supporting a special operations unit down there. I had a very senior guy with me too, just in case something happened, you know, he could still fly the airplane. If somehow my ileostomy exploded in flight. Also had senior crew with me on that one just to kind of monitor me and see what we could do.

Lt Col Joshua Nelson 19:14

So one of the lifts that we did with personnel is we had to go to 25,000 feet on pressurized. And our books tell us that if we go above 20, I need to pre breathe oxygen for 30 minutes, and I can't get, I have...what was the term? I can't get above 16,000 feet or I'm sorry, 20,000 feet on pressurize until I have 16 minutes of 100% oxygen. Really what that does is it gets rid of the nitrogen in your blood. So when you come on down and decrease it decreases the chance like a decompression sickness.

Lt Col Joshua Nelson 19:46

So I have my oxygen mask on [breathing noises]. You know we're sitting on the hoses breathing this stuff in and that's the time we went up to 25,000 feet we kind of go up slow, you know because sinuses, ears. We don't want to do any damage to people on that. But that's when I said, oh my, what is my bag doing, and I touched it — completely flat. And the reason why that was is because before I hopped on the airplane, I always empty the contents of my bag, even if it is empty, because the bags are so nice now to where you can pretty much squish out all the air that may be in your bag.

Lt Col Joshua Nelson 20:21

If I am flying for longer duration, I find those foods that slow my system down rice, oatmeal, stuff like that, I will prepare myself for that. And so knowing that I can go up and down from 25,000 feet all the way back down the bag, not doing a single thing gave me a lot of confidence that I can still do everything. We can also take the seat 130 down to 300 feet above the ground doing 250 knots, and then slow down. And the high G's that they were talking about in G's are kind of like the force of gravity pushing on your body if you maneuver an airplane in flight. So they're like high G's like the airplane is rated for two and a half. If I do three wings are falling off. So it's like, that's not even there.

Lt Col Joshua Nelson 20:59

In general, when you do high G maneuvers, you wear a suit around your abdomen and the lower portion of your body because that helps prevent the blood from pooling to your extremities. If I was a fighter pilot, I could see where that could be an area of concern because my ileostomy says right around that abdominal section. So if that suit inflates, I could have a leak or blow up per se. And then a lot of the other ones were just well, by the way, if I need to empty the contents of my bag, good thing I got the bathroom in the back. We are a crew, so if something were to happen, which nothing has yet, there's someone else who can fly the airplane.

Lt Col Joshua Nelson 21:33

And the other thing I wanted to bring up to a lot of people is, especially with flying commercially, is the fear of, like, gas forming and the bag expanding. And my knowledge of airplanes when it comes to pressurization as the example I used to say you depart Minneapolis, the sea level altitude is about 800 feet above sea level. So generally, when you depart the location, you set the pressure altitude about 1000 feet, your worst case scenario is going to be going from like Minneapolis to let's say, Denver, Denver is about a mile in the air 5000 some odd feet above sea level. And so when they descend, they will put that pressure around that sea level arrival, so in theory, the pressure does not change a whole lot in flight, we're maybe talking one to 3000 feet at most. One thing I try to tell people just prepare yourself, for, you can always carry supplies with you. Don't be afraid to use the bathroom because everybody on the airplane is using the bathroom.

[MUSIC: About IBD Transition]

Amber Tresca 22:36

If someone else were faced with the situation that you were faced with, and was needing to go through this process to get reinstated, what kind of tips would you give them in order to bring it around so that they could get back to their military career?

Lt Col Joshua Nelson 22:51

100% percent be completely open and honest about what is happening. Your leadership, your medical support staff start talking to people about what issues that we need to overcome and full displayed disclosure disclaimer out there. Every situation is different. In theory, there's kind of two processes, number one is gonna have to run through the medical process. And if you're

ultimately deemed disqualified, then there is another way, it's called the exception to policy process. And that's where the general officers, the people who were the stars on their shoulders, can override decisions.

Lt Col Joshua Nelson 23:26

But we needed to wait for the medical process to run its course first, before we could run the exception to policy process. Luckily, I never needed to get there. We are a volunteer force. The military does have the right to list medical requirements. Because at the end of the day, we need to be able to deploy, we need to be able to do our job at a moment's notice. And that could be in areas and locations that aren't co-located to a military treatment facility. You might be on your own for weeks at a time with bare minimal support. As an instructor in the C 130. I'm still usable, it may not be actively flying an airplane in a deployed location. That could be part of the support staff, you know, things can still be done. If I was at my, you know, seven, to eight to nine to 10 year mark, could that decision have been different? I think so. Like we were completely prepared to accept the disqualifying condition, but I wasn't going to go down without going toe to toe with people. I would have been completely satisfied if I gave it my best, everyone still told no, because at least I tried.

Lt Col Joshua Nelson 24:36

All I can say for people who are going through this, there are resources out there that you can find. Your medical support staff has all the information that you need, It is unnerving hearing stuff such as you know an assignment duty limiting Code AC, 1C, 2C, 3, that kind of restricts to what you can do. It is it is under a disqualifying condition. But A lot of things can be waived, which is what happened with me, the flight waiver is a waiver to a condition that I had. And if I looked up the verbage for ulcerative colitis for those who have had a colectomy me, it says on there that they are granted on a case by case basis. So just that verbage right there means that is not the same for every everybody who has it.

Lt Col Joshua Nelson 25:21

But I try to tell people there's more to life than just serving in the military, I get it's fun, the camaraderie is there, and this is what people want to do. But health is what's important. Family is what's important. Finding something, you can always find something else to do something that will make you happy. But none of that stuff is gonna matter if you're not healthy, if you're sick. If you're struggling with active disease, or you don't have the support of even your own family, it's gonna make things a lot more difficult. So my recommendation to a lot of people as always is to be open and honest with yourself. Forget about what you're doing right now and focus on what can I do to overcome and manage this disease because that that maybe it'll take you down.

Amber Tresca 26:05

Josh is grateful for the technology that saved his life and allowed him to continue with the career that he loves. He found that being adaptable and open with everyone around him, from his colleagues to his family, led to a better outcome. He has a message of hope for others who may be facing surgery for their IBD.

Lt Col Joshua Nelson 26:24

But I can truly say my life has not changed or nothing has changed for me having a ileostomy flying an airplane with now versus what it was before. I cannot tell you how pleased I am with the surgery, the results I've had. I'm not afraid to jump in the water. I swim with the girls all the time. I tell people that there's nothing to be afraid of having an ileostomy. I mean, I wear mine vertical half the time with the stealth belt is what I use. It saved my life. It gave me my life back. I think if you asked my wife, my two daughters seeing dad get sick was probably not an easy time for them and wondering what our life is going to be like if we cannot overcome this, to what I am now, is you're happier. Because I'm not scared anymore. I'm pretty fortunate.

[MUSIC: About IBD Theme]**Amber Tresca 27:17**

Hey, super listener. Thanks to Lieutenant Colonel Joshua Nelson for sharing his story. His experience shows us how ostomy surgery is a life saving procedure and that it's even possible to fly Blanes if you have a stoma.

Amber Tresca 27:33

Links to more information about the topics we discussed is in the show notes and on AboutIBD.com.

You can follow me across all social media as AboutIBD. If you want to leave me a voice message for use on a future show, you can contact me at speakpipe.com/aboutIBD.

Amber Tresca 28:10

Thanks for listening, and remember, until next time, I want you to know more about IBD.

Amber Tresca 28:12

About IBD is a production of Mal and Tal Enterprises.

It is written, produced and directed by me, Amber Tresca.

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