

That's Hysterical! Now Get Out!

SEASON 1 | EPISODE 5

Navigating Adenomyosis FB Groups and Swedish Death Cleaning

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It's just Adenomyosis again. Adenomyosis again. Adenomyosis again. It's Adenomyosis. You're not going to die from it. But no one really knows because there's not enough research. On this episode of That's Hysterical! Now, Get Out! I made the mistake. I've been looking at a lot of success stories and they've been coming up on my feed naturally. I guess the algorithm got the hint like show her, his direct to me, success stories because she sits there and reads the comments so we get her engaged. So the algorithm knows that. That's how algorithms work. They work to keep you on the app. So always remember that whatever you engage with the most, you're going to see the most because the algorithm, a human-programmed AI bot essentially, is creating that pattern of view and trying to replicate it. But I made the mistake of going to the actual adenomyosis group and looking at all the posts, not just the success stories. And it was interesting going through them because right now, I'm just focusing on the success, on the after because it's really hard not to question this decision of did I do the right thing, getting the surgery?

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Am I doing the right thing? Am I going to make things worse? There's a lot of fear going on in my head. And in fact, I spent most of the morning doing more Swedish death cleaning. It started with my closet last night. It went to my fridge now, my countertops. I think my nerves are going a little haywire, and I can feel basically all those diagnoses from therapists. There's the ADHD, there are the OCD tendencies, there's the compulsions, the picking at my face, the biting my lips, the biting my cheeks, the cleaning, the just one more thing, the not paying attention to time or what I need to be doing or where I need to be because I'm stuck in this hyper focus of just one more thing, just one more thing because this is making me happy. Cleaning is making me happy. The idea that I will be in recovery and my house will be clean was making me happy today. And I love focusing on the idea of when I'm in recovery, I can tell my husband, Hey, can you go to the hallway closet and to the left on the shelf with all the medicines?

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There's the gas relief or in the medicine cabinet in the bathroom, there's the stool softener. Knowing where that stuff is, having that clear mind right before surgery, going into it, setting myself up for success during recovery. I'm trying to paint it as a bad thing. These are my compulsions. I'm compulsive to do this. And I think I'm more worried that I'm wearing myself out because I'm doing more physically than I think I have in a long, long time when it comes to really cleaning and getting stuff ready and prepared. And what's funny is my house is still a disaster. If you look at the laundry, Oh, I can't do that. Right now I'm on the couch, it may or may not be the first day of my period. My period is playing this nasty little trick on me

at this time. It knows it's the last period. It is bleeding, but it's also not. I'm also questioning, is it bleeding from the biopsy? Who knows? I have all these thoughts running through my head. My anxiety is through the roof, my compulsions, I'm picking up my nails more. They look awful. One of the things that I think an an oasis did or does or all the pain and discomfort from it is it really wreaks havoc on your mental health because not only is it your physical health, but there's this pain inside of me that pulls at my brain of like, Hey, hey, hey, hey.

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Feels like someone's stabbing us. What's going on? It's just pain. That's a bad thing, right? We shouldn't be feeling that. And it's like this logic side of my brain is putting this record on repeat of it's just adenomyosis again, adenomyosis again, adenomyosis again. It's adenomyosis. You're not going to die from it, but no one really knows because there's not enough research. It's hard to say and hard to spell, but the more you know, the more you can tell every doctor you ever talk to, because they're going to google it as soon as you're outside the door, and they're going to wonder why no one ever researched it before or talked about it before. Anyway, yeah, that was my morning. That brings us to now where I was looking at Facebook and I went to the adenomyosis group and I was looking at success stories and then I was looking at people in the beginning stages where I remember being about three years ago hearing the word adenomyosis for the first time, making their first post, asking questions, not really going for the search bar, but I think really looking for that connection. And it's funny because as much as I'm having this very complicated relationship with social media at the moment, I remember being in that group and searching through all those posts and doing all that and trying to read the room of who knew what they were talking about and who didn't and who guessed and who liked to base everything they said on their own personal experiences, regardless of science or doctors or trained professionals, all kinds of people post online.

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I think social media gives a very skewed idea of the people who are actually in those groups and the sample size and who's actually experiencing what and the numbers of people actually experiencing what. It was one of the first groups that I really just did a lot of lurking. I don't know if I had many posts other than when I was first really learning about adenomyosis. I read a book by Maria Yeager that I'll link to about adenomyosis, and I think I was pretty helpful in the group for a while. Then it got to more and more of the posts of I'm just finding this out. I don't know if I'll be able to have kids. I'm having all these tests. I'm doing all these things. It's not working. It's not working. It's not getting better. It's getting worse. How many more things do I have to try? This is making me anxious. This is making me fearful. This is giving me anxiety. This is giving me panic. This hurts and hurts. Childbirth wasn't even that bad. After a while, reading it got to be a lot on top of experiencing it. At first, I was really excited when I was learning all about it, excited because maybe, okay, I could have some answers.

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I could change some of my diet around and get more cruciferous vegetables into me. That was the big thing, cruciferous vegetables. And to be honest, yeah, they do help. We need iron. We need so much iron. Oh, speaking of which, I need to take my iron right now, and I should do that. Take my vitamins. And that'll be another thing people bring up is not just the medical things. They've tried the supplements, the snake oil, the essential oils, the bracelets, the jewelry, the crystals, the goop recommended women's health shit, for lack of a better word. Sorry, Gwyneth. I'm not sorry, though, because at one point, I think I was desperate enough to think that maybe a fucking rose quartz egg in my vagina would be the way to go to get rid of this adenomyosis. Maybe at one point. I could understand the desperation, to be perfectly honest. There was a gas bubble I had about an hour ago that just made me more sure than ever of this surgery coming up. I'm actually at the point now where I think I'm coming down from that Swedish death cleaning energy I had this morning. And I've gotten to the point where I figured out that I just need to work and work and work on my client's stuff.

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They've all been very understanding, but at the same time, I want to get ahead as much as possible. Also, it'll keep my mind off of things. I think that's a good thing. Doing my work is actually one of the healthiest things I do. Well, not working too much, but my actual job working on podcasts for the most part, they're all very feel-good podcasts, so I'm not sitting there distracting myself with more pain and suffering. I think that's why I had to get out of newspapers eventually and maybe out of podcasting altogether. Who knows? I don't know about the podcasting space at this point, but my clients remind me that there are still people out there putting out amazing podcasts for people helping them. I hope that's what this is. I think that's what the adenomyosis group was, and it still is for me. Absolutely, still is for me. But there was that period of time where I couldn't keep reading how it got darker and darker and experiencing it and having what has turned into three weeks out of every month of pain and suffering. One really, really, well, two really, really bad weeks. But then I would go on Facebook during that one week, right after my period, when the energy and I'm feeling great, I'm feeling good.

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And I go on to Facebook and then I see a post of somebody who just found out they had adenomyosis and they're so worried that they can't get pregnant or they're finding out about adenomyosis and maybe they're wondering why they have to fight their doctors and their medical professionals to see somebody who will actually take them seriously and not just put birth control on them and give them a hysterectomy if they're 29 and don't plan on having kids because I know that there are situations like that. That's one of those things I haven't quite touched on yet because I feel like it is something that I haven't been able to get fully as angry about as I really, truly am, because I'm just dealing with all the other shit I'm angry about and upset and worried and anxious about. But I believe one of the episodes is definitely going to talk about how the fact that I'm 40, it was almost like with every doctor, no matter how much I liked them, every medical professional I talked to, there was always they would go through the list of, okay, so you're over 40, you've had two kids.

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I'll even sometimes say a boy and a girl, and I'm like, What checklist is this? I understand that people come up with, I think, a quote-unquote, default. This is what adults do. This is what adults have. Adults grow up and they have kids. And if they have a boy and a girl, they're all set. They have one of each. Hello. There are many, many. I'm not even going to... Don't even come at me. I'm starting many sentences because I'm fighting many battles right now of don't come at me with what is the definition of I don't care. He, she, they, them. They're all welcome to me. They're all welcome to listen to this podcast. And you know what else? Just come in close, listen to this. Women aren't the only ones who get adenomyosis. Oh, what did she just say? Yeah, I said it. So if this is your cue to leave, if this is what prompts you to leave a review, thanks for the engagement. Just know you're helping the show whether or not you give a good or bad review. Thanks. But if you decide that this is where you leave me, good.

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Good. I've been talking about Swedish death cleaning. I've been writing my in case of death documents. I'm in that mindset of at this point, those people who have a problem with the fact that I say things like that and believe things like that, they can get the hell out. They can stop listening to my free podcast that I put together from the love of my heart and my uterus, my agnostic little heart uterus. I don't know what that is. I think I've been listening to too much Tara Brock, who puts together your body, mind, your heart, soul. So for me, it's my heart, uterus. Anyway, I want to leave you with this. If you do happen to want community, I don't know when you're listening to this, what platform you're on. There are a lot of great adenomyosis communities where people are very helpful. There's the one on Facebook called the Adenomyosis Advice Association discussion group. I could be wrong. It was a long time ago. But one of the things I forgot to mention was during that time of real big excitement about learning everything about adenomyosis and how to help myself and finding all the people getting excited about it, I was like, I'm going to start a podcast about it.

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I did all the things. I made all the art and bought the domain, made a bunch of creative stuff. I might still use it for this podcast, who knows, in some manner or capacity. But yeah, at one point, I think I have an interview from the creator of that group, in fact. I interviewed her for the podcast I was going to do, and I interviewed the director of a short film called Hysterical Sisters that I'll also link in the show notes because it's phenomenal, and it is about adenomyosis. Anybody who's experienced adenomyosis or know somebody with adenomyosis, they will, I don't know 100%, but I think they will see themselves in at least one or two characters. I will leave you with that, folks, and make sure to rest if you've been up all day on your feet and you've been running around. I can't tell you how nice it's been for the last 20 minutes to sit down with my heating pad on and focus on creating this for other people and also so that I give myself a break because I hope in about two, three months, maybe even a week from some of these posts, I have really high hopes right now.

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I hope I'll be writing my own success story and then I'll be thanking everybody who wrote theirs because that's what I need and maybe this is me asking the algorithm of the universe like, Hey, I need those success stories to get me through at least. I know there's complications. I'm planning for some of them. That's why I went to Target and spent a ridiculous amount of money on like, Let's make sure there are all the snacks in the house. Let's make sure there's gas relief and stool softeners and the stuff I mentioned that are top of mind right now for me because every day at this point, it seems like so many details cramped all at once. It's amazing the organization you do when you're like, Am I going to care about this in six weeks when I'm recovering and I don't remember this is in the back of the fridge? No. Why don't we just throw it out now? Because I'm already not interested in it. Anyway, take care, folks. I appreciate you, and I appreciate you being here and finding your community of other adenomyosis warriors. Take care.