



30 JAN, 2025

INTIMACY with ILLNESS

Take 5, National



Take 5 report

Life with Shannon and our kids is wonderful

Breaking the stigmas surrounding sex and stomas

INTIMACY with ILLNESS

Dating can feel daunting at the best of times, but imagine the difficulties faced by those with an inflammatory bowel disease (IBD), like Crohn's disease and ulcerative colitis. The lifelong gastrointestinal disorders cause painful

symptoms, including chronic diarrhoea, abdominal pain and fatigue. Data from Crohn's & Colitis Australia reveals Australia has one of the highest rates of IBD in the world, with 100,000 people affected. Of those affected by Crohn's disease, 80 per cent will eventually need

surgery. For some, part of their bowel will be removed, and they may have to live with a stoma bag, which collects their faecal waste. While surgery can alleviate the pain, living with a stoma bag isn't without its challenges, especially in the realm of dating, sex and intimacy. To

start a conversation which has long lived in the shadows for IBD sufferers, Take 5 has spoken with those living with the disease, and experts who share tips on navigating life with a stoma bag, in and out of the bedroom. *For more information, visit: crohnsandcolitis.org.au*



It's vital to love yourself first

Sex with illness

Clinical psychologist and couples therapist, Phoebe Rogers says experiencing the new look of your body following stoma surgery can bring shame and embarrassment. But withdrawing from social situations or intimate

relationships can erode self-esteem and mental health.

A period of adjustment should be expected, and feeling grief is common.

"A raft of feelings can emerge, from sadness, anger and even depression," Phoebe says.

She says taking a kind approach can help.

"I encourage clients to think about how they might love and accept themselves even if their body has changed," she says.

When it comes to intimacy, although it's natural to feel nervous, Phoebe reminds couples they're on a journey.

"Openness and honesty



30 JAN, 2025

INTIMACY with ILLNESS

Take 5, National

ZERO SHAME!

Rhiannon Jones, 30, Wilmington, SA.

Taking a sip of my bowel prep, I groaned.

"It's so unfair," I said.

"I know, darling," my mum Andrea, 41, replied.

While my friends were celebrating schoolies, I was preparing for a colonoscopy.

I'd been suffering from chronic diarrhoea throughout my teens.

I tried lactose-free and gluten-free diets, but nothing stopped the frequent trips to the loo and crippling abdominal pain. Embarrassed, I tried to hide it from my peers.

I had the colonoscopy, and afterwards the gastroenterologist called Mum and me into a room.

"It's perianal Crohn's disease," she said, explaining it was a type of inflammatory bowel disease.

They wanted to remove my large bowel.

"So I'll have to walk around with a poo bag?" I said. "No way!"

I was so horrified, they gave me medication to reduce the inflammation.

Later, I started dating Shannon, 19, who I'd known from school.

He had an older brother with cerebral palsy and had grown up understanding what it was like for someone with a disability.

I'd hidden my IBD from past boyfriends, but I confessed it to Shannon.

"There's nothing to be embarrassed about," he said kindly.

The meds I was on worked, but I suspected I was on borrowed time.

In August 2018, Shannon and I had a son Maverick. We married soon after and in August 2021, Elke was born.

Over the following year, I became very unwell.

"It's time for your bowel to go," my colorectal surgeon said.

I woke up from surgery without my large bowel, and with a stoma bag. I had no choice but to accept it.

Thankfully, Shannon was all for it. Before moments of intimacy, I'd empty my bag



I had no choice but to accept it

and velcro it out of the way. Later, as the disease had seeped into my rectal stump,

I had surgery to clear it out, remove my anus entirely and stitch it up.

I'm still recovering and will live with a stoma forever, but I finally feel at peace with it all.

While my wound heals, Shannon and I have gotten creative with intimacy, but I'm confident we'll be back to normal soon.

I'm healthier now than I've been since I was

little. I feel zero shame around my stoma bag, even wearing crop tops.

It's given me my life back. No more pain, no more fear or always wondering where the closest loo is.

"It's great to see you so happy," Shannon said.

I'm so lucky to have him. Dating with a chronic illness isn't easy. Be honest and pick a supportive partner, because they make such a difference.

WHAT IS A STOMA BAG?

A stoma bag is a plastic bag worn outside the body that collects faecal matter. A stoma is an opening made through the abdomen which connects the bowel to the surface. A stoma bag creates a seal around that hole, to catch stools and prevent skin irritation.

Turn for more

are key," she says. "Each person may have different feelings about what's happening, and talking is a pathway to intimacy."

For singles hoping to date post-surgery, the prospect of revealing this aspect can be daunting.

Although honesty is best, disclosing too much too

soon, or not at all, can be problematic. Phoebe says it's best to test a person's maturity gently, to see if they're emotionally able to respond to illness or physical differences.

Perhaps make it as simple as asking a person's view on mental health or anxiety.

"Their response can

indicate their values," Phoebe says. And for those navigating intimacy, some days sex will be feasible, and on others, it won't.

"You're the best judge of your body," she says. "And it's your responsibility to care for yourself."



30 JAN, 2025

INTIMACY with ILLNESS

Take 5, National



Take 5 report

Me with Jordan and Daniel - we're so happy

LEARNING TO LOVE MYSELF

Jade May, 38, Redfern, NSW.

Staring at my stoma bag, a lump formed in my throat.

"How will I find a boyfriend with this thing?" I said to my mum, Josie, 46.

"You will," she replied, but seemed unsure.

At 20, my self-esteem was at rock bottom. Diagnosed with Crohn's disease seven years earlier, I'd been in and out of hospital ever since.

Now, due to complications, I'd had part of my small intestine temporarily pulled out while my body recovered, and a stoma bag inserted. It was painful and I never got used to it.

I read romance fiction to forget about it. They taught me about kink and bondage,

and I could explore what I might like sexually - not that I'd had real-life experience. I'd never even kissed a boy.

A year later, I had reversal surgery and the small intestine reinserted, so the stoma was removed.

Medication controlled my disease though I knew future surgery was likely.

I got a marketing job and joined some dating apps. But I didn't hit it off with anyone.

At 28, I met a man called Daniel, 35, at a work conference on the Gold Coast, Qld.

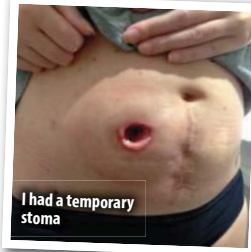
Turned out, my colleague Catherine knew him. "He's the sweetest guy," she told me.

That night, Daniel approached me. It sounds cliché, but I looked into his eyes and fell in love.

"Can I buy you a drink?" he offered.

"Sure," I grinned. As we chatted, I'd never connected with someone like him before.

Afterwards, he flew back to Sydney and I went home to



I had a temporary stoma

Melbourne, but we stayed in touch. Weeks later, he convinced me to fly to Sydney for the premier of *Anchorman* which he was working at. There, we shared our first kiss and I knew I had to tell him about my illness.

It's tricky - tell someone too soon, you risk scaring them off. Too late, and they think you hid it.

"I have a chronic illness, and it comes with a lot of baggage," I said. Daniel nodded as I spoke, taking it all in.

"I understand," he said. *Do you really?* I wondered. He revealed his sister, Leah, 29, had sadly died from Hodgkin lymphoma. I saw it gave him a level of empathy many blokes wouldn't have.

When we were intimate,

I looked into his eyes and fell in love



I knew surgery was going to be my path

DOCTOR'S TIPS

Gastroenterologist Dr Reme Mountfield says most of the time, people living with a stoma can have a normal and healthy sex life. Establishing open communication with your partner about the stoma, what it looks like and why it is needed is important to accepting it and needn't interfere with sex.

Here are her top tips:

- Speak to a stomal therapist. They're a great resource to answer questions and dispel myths.
 - To start a conversation with a prospective partner, you could show pictures of stomas online to prepare them.
 - Reassure them a normal sex life is possible and won't harm your stoma.
 - Empty your stoma bag before sex if possible to reduce distraction.
- As more people talk about managing sex and relationships with a stoma, the broader community develops more awareness - with this comes greater acceptance, compassion and understanding.

I was incredibly worried I'd have a bowel movement.

Daniel was very patient and after several months, things got better. We married in 2015 and three years later, we had our son Jordan.

My advice to others with a chronic illness wanting to date is to go for therapy first.

It took me years to confront my trauma and love myself. I wish I'd done it sooner.

If you can't love yourself, you can't love anyone else.

AS TOLD TO EMILIA MAZZA AND CANDICE HABERSHON