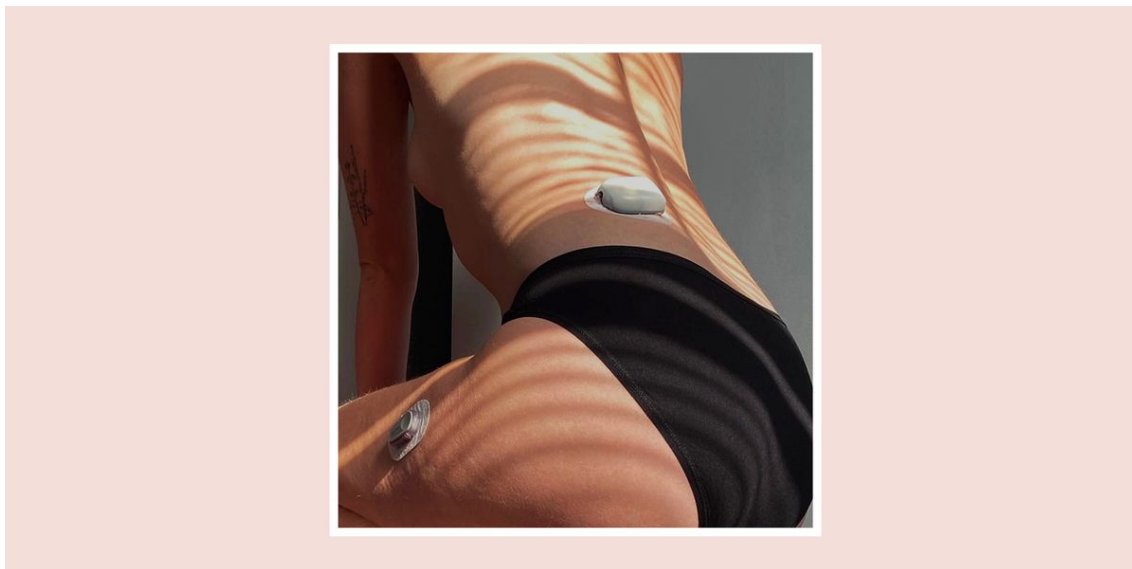


# The First Time I Had Sex After Getting Diagnosed With A Chronic Illness

"Acknowledging my illness instead of *ignoring* my illness led me to a new level of freedom—and even a new level of pleasure."

BY KELSEY RHODES PUBLISHED: NOV 30, 2022



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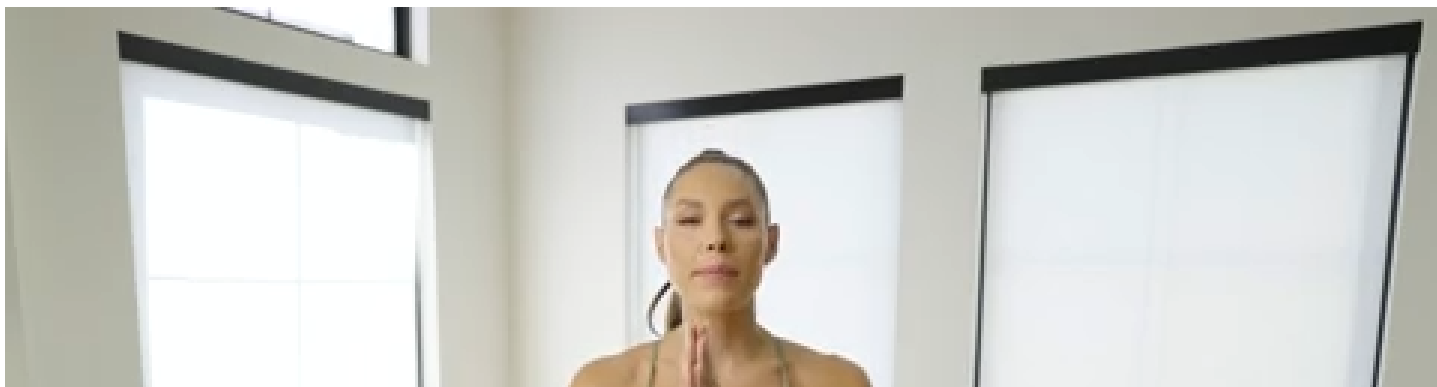
Looking into the curls of her salt and pepper hair tracing my ribcage, I whispered, "I'm so sweaty." My partner and I had spent an entire sunny Sunday afternoon watching Netflix, and after toes rubbing on toes and a few slow kisses, it was clear what our next weekend activity would be.

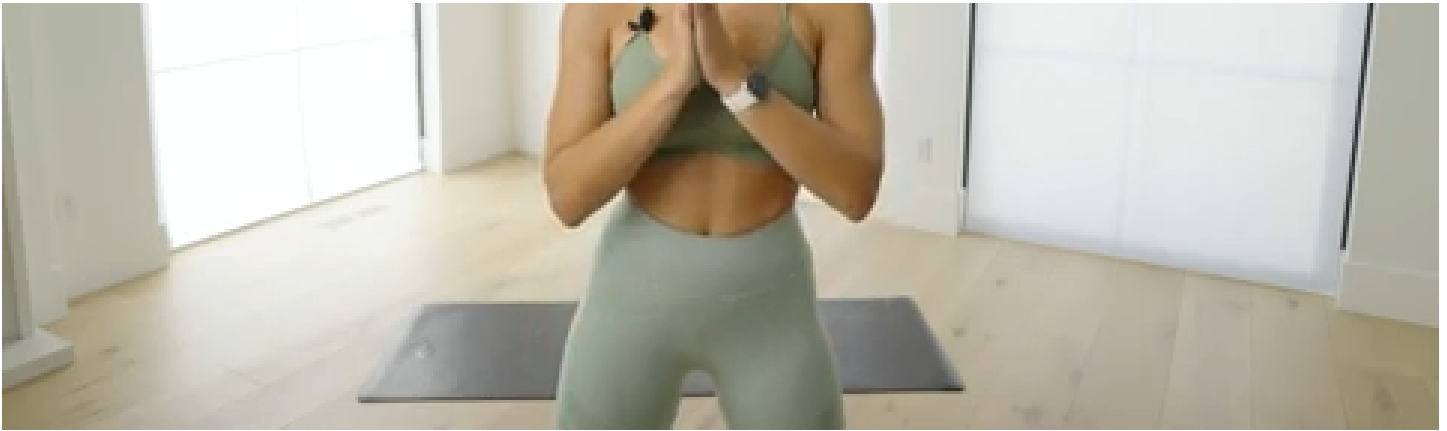
Her lips and tongue made snail trails down my abdomen. I could tell my breaths were getting heavier, my body riding its own waves. And then, a loud, startling alarm—followed by four piercing beeps—screamed from the phone teetering on the edge of the nightstand.

The last beep and buzz sent my phone tumbling to the floor next to our bed, and we no longer were able to ignore what we'd tried to forget for the last nineteen minutes: She was having sex with a sick person.

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Specifically, me, a Type 1 diabetic with Celiac disease, Grave's disease, *and* Hashimoto's. Me, a chronically ill, 30-year-old, queer, cisgender woman. The beeping was my blood sugar alarm, my blood sugar was dangerously low, and all that sweat was actually from hypoglycemia, an urgent health event when your glucose level drops below the standard range of around 70-100 mg/dl. When blood sugar drops below 70 mg/dl and is untreated, diabetics can lose consciousness. It's serious, scary, and definitely not sexy.

## **Two years prior, I started spending an increasing amount of time in doctors' offices for a mystery illness.**

While my primary care physician said it “must just be depression,” I knew what anxiety and depression felt like to me—and the thinning hair and rapid weight loss wasn't it.

My then-husband spent so much time consoling me, making space for my increasing anxiety about what was wrong and why I was feeling so sickly after eating. His father had recently been diagnosed with Type 2 diabetes, and one day, when visiting his family's home, we each went around the table and checked our blood sugar. A healthy, non-diabetic's blood sugar is always right around 100 mg/dl, ranging from around 80-110, but always staying within those limits and quickly returning to the home base of 100. My ex-husband's, for example, was 102.

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Mine was 217.

Upon returning home, I went back to my doctor, and five days later, I was diagnosed with Type 1 Diabetes—the kind where you have to replace your failing pancreas’s job with injections of insulin every time you eat.

A lot changed after my diagnosis: I got divorced, moved across the country, and navigated a new relationship, along with new identities as both queer and chronically ill. While I was relieved to have finally “solved” my mystery illness, I wasn’t prepared for how life-changing it would become for literally every part of my life, including sex.

When my endocrinologists first sat down with me and explained my disease, they explained what to expect in my body. They showed me how to ask my friends and family to show up for me mentally and emotionally, a conversation I would later rehearse again to have with my current partner. They taught me how to dose my insulin depending on how many grams of carbohydrates I was eating, if I was stressed, if I was exercising.

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## **But my doctors never shared the new obstacles my diabetes could bring up with libido, arousal, and navigating intimacy with a sexual partner.**

It’s not for lack of research: Challenges with sexual experiences is super common in folks with chronic illnesses. [Take this 2019 study](#), for example, which shows that sexual desire, arousal, and the occurrence of orgasm all decrease with the onset of chronic illness.

The findings of the study closely parallel what I experienced over the course of getting sick, getting diagnosed, and discovering new coping mechanisms: I knew I had a body, but all I knew was that it wasn’t working how I wanted it to work. My internal dialogue shifted away from what brought me pleasure and instead was filled with old-fashioned cash register sounds of adding grams of carbohydrates with grams of fiber and doing a mathematical feat to figure out how much insulin I needed to shoot into my skin before eating.

# I knew I had a body, but all I knew was that it wasn't working how I wanted it to work.

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Sex became a multifactorial calculus of making sure that my blood sugar levels were in a safe range (overexertion makes them drop) and that, in addition to keeping lube and sex toys within a naked arm's reach, I also had insulin (in case my blood sugar was high) and gummy bears (in case my blood sugar plummeted).

In short, sex became a risk—another thing to manage. In the year after my diagnosis, whenever I felt my stomach drop right before orgasming, I would often second-guess whether that was from pleasure or from a medical emergency—and then I'd cringe, waiting for the alarms to interrupt an entanglement of joy.

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But no one wanted to have serious conversations with me about how much my diagnosis had impacted my thoughts around my sex life and relationship to sexuality.

## Amid a new list of physical and mental complications, I realized I had to relearn sex altogether.

While it feels extremely vulnerable, there's a new level of tenderness to be found navigating sex with a trusted partner while chronically ill. For me, acknowledging my illness instead of *ignoring* my illness led me to a new level of freedom—and even a new level of pleasure.

The first step was getting to know the new me (with all its technological extensions), and appreciate those devices for helping me live. I wear two medical devices on my body at all times, a la Lila Moss, but make it way less fashion. One continuously monitors my blood sugar, and the other doses me with insulin. They connect via bluetooth, and only work when I have two additional devices nearby for readings: my phone and a transponder that also looks suspiciously like a phone. The devices have to be changed and moved to new locations on my body; the monitor every 10 days, and the insulin pod every three.

While technology has made giant leaps and bounds when it comes to the life-saving qualities of diabetes wearables, these aren't like a smartwatch that you can take off and leave on the bedside table before trying out a new sex position. They're a part of me. I have small bruises from insertions and pock marks where the small flexible cannula pierces into my skin for each three-day lifetime of the pump and each ten-day life of the glucose monitor. The thin straws eerily float around in my subcutaneous fat layers, reading my blood sugar and dosing my insulin, keeping me alive.

So yes, while it is cool—and, more importantly, essential—it's hard for me to find anything sexy or sexual about being a cyborg, especially as someone who's not that into roleplay. The first few times my current partner and I had sex, I was painfully aware of my plastic pieces and the way the adhesive pulled when she rubbed her hand across my bare skin. Sex also became a potential risk for my devices to rip off, an experience that has to be dealt with pretty immediately. Imagine: a call to the medical device company for a replacement, a brief awkward decision of whether or not I'd lie about the reason for why it fell off, and finally, the hope that my insurance would cover the replacement. I don't know about you, but I've never had a sex dream about calling my health insurance representative.

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## **Plus, there's an emotional component to having sex while chronically ill, too.**

My partner has expressed a fear that she'll accidentally rip off those devices or otherwise hurt me, and I've also found myself asking for a lot of reassurance and apologizing for interrupted play.

It took several months of having every sex experience feel brand new—even if it was the same partner, same position, same environment—to get anywhere near celebrating the sex that emerged from acceptance and self-love. There were countless nights spent second-guessing whether my partner was truly attracted to me *and* my gadgets; memorizing the differences between what symptoms of my illnesses felt like, versus sensations associated with excitement and pleasure; building sacred rituals around making sure my body was physically ready to have sex.

## **Ultimately, though, having sex while chronically ill ended up giving me a deeper awareness of myself.**

Specifically, I discovered a previously-untapped wealth of sensation, of desire, of creative ability. Having sex while chronically ill is a constant reminder of all of my strengths and how they are deeply and intimately mine. It's powerful to be in touch with how far I can push myself, and to find safety in saying, “not right now.”

My illnesses give me a more diverse vocabulary with which I can navigate consent with my partner. There's a vast freedom in having conversations that are driven by real bodily and emotional needs. There's new humor in the varying Haribo bags, little caramels, and partially-eaten chocolate bars that now always live in the drawer next to my bed. And it feels so good to laugh with someone who loves you, and who you love so deeply in return.

I'll never be able to have the kind of carefree sex I had when I was younger, before I knew I was sick. Sex is now a part of my continual adjusting of expectations from what the world tells us things *should* feel like versus what they *do* feel like. And there's some grief that comes with the fact that I'll never figure out how to return to a time when sex can come on a whim, a surprise to my day in the throes of passion. This is me, now. I'll never be healed; I'll never be completely “healthy” again. I'll have to keep navigating “coming out” as chronically ill, sick, or disabled, and there's a deep risk of being abandoned in those moments.

## **Having sex while being chronically ill ended up giving me a deeper awareness of myself.**

But what I wish I knew when I received my first diagnosis is that there's a special opportunity to know myself in a new way, verbalize my needs, build relationships with care, and, yes, have the best damn sex of my life. And none of this is in spite of illness, but because of it.