

Sex

When my sister and I were 14, pre-Hypermobility Ehlers-Danlos Syndrome (hEDS) diagnosis, my sister saw a pediatric rheumatologist who evaluated her hypermobility (and ignored her chronic pain) and quipped that her extreme flexibility would make a man very happy someday. While this is obviously wildly inappropriate, it is in line with where many peoples' brains go when they think about hypermobility. And I'll be honest - it's true. The ability to contort into all sorts of positions can be a plus when it comes to sex - but it can also contribute to painful and debilitating injuries and fatigue and a host of other issues.

When I was 30 years old, I went to see a new Primary Care doctor who, without asking me any questions about my sex life and based only on the knowledge that I have hEDS, strongly recommended I buy dilators. Specifically, these [dilators](#). In my more than two decades of seeing dozens and dozens of medical providers, this was the first one who made any effort to acknowledge that sex can be tricky for people like me and that sometimes a bit of help, education, and/or creativity is beneficial. While this doctor was less than graceful in his delivery, I appreciated his thoughtfulness and awareness that having certain chronic conditions - and certainly one that affects literally every inch of my body, inside and out - can affect sex.

How Chronic Illness Can Affect Sex

- Fatigue
- Pelvic floor instability
- Pain, injuries, inflammation, swelling
- Hives, rashes, itching (head to toe, inside and out)
- Libido challenges, erectile dysfunction, difficulty with arousal and feeling safe
- Shortness of breath, difficulty and discomfort breathing
- Heart palpitations, tachycardia, hypertension, hypotension, fainting, dizziness
- Nausea, bloating, abdominal pain and/or cramping
- Neuropathy, difficulty interpreting and processing sensation, discomfort or pain with certain sensations, tingling, numbness, burning
- Patient / caregiver dynamics interfering with sexual chemistry
- Stress and trauma

Partners and Communication

I participated in Facebook support groups for my various conditions for many years, and observed that people with chronic conditions often feel unsupported in their romantic (and platonic) relationships. They worry that their health will prevent them from having fulfilling relationships and sex lives. I've heard stories online and in person about people with chronic illnesses feeling shame around how their health affects all aspects of their lives, including their sex lives. I've also heard about partners being less than supportive of the challenges that need to be navigated - and that absolutely can be navigated if you're open to having open, honest, vulnerable conversations and ditching stereotypes and culturally-influenced expectations.

I was overcome by all the pain that so many people were experiencing, and it didn't help that I had a boyfriend who made me feel like I was lucky that he "put up with" with my health issues. I began to develop my own fears about long-term relationships, wondering why anyone would voluntarily take on my

complicated and challenging life. I eventually stopped participating in those support groups because the volume of anxiety overwhelmed the positive benefits.

When I was 27, I met my now-husband who immediately squashed any fears that I had developed about being “too sick to love.” Having the right partner makes all the difference. The right partner is someone who you can have ALL the conversations with, and whom you don’t feel embarrassed to tell what’s happening with your body and what your needs are.

My love and life with my husband are dreamy. It’s important to me that people living with chronic conditions know deep in their hearts and souls that they shouldn’t settle for a life or love that is less than what they dream about.

Spontaneous v. Responsive Sex Drive

Health status aside, there are different types of sex drives - and understanding your sex drive type can make an enormous difference in how you and your partner communicate about, navigate, and understand your joint sex life. While an individual is capable of experiencing both types of desire, most of us tend to experience one type more frequently than the other. Understanding and communicating about your and your partner’s sex drive type can be an important part of having a fulfilling sex life.

Spontaneous Sex Drive

- You feel the desire for sex at seemingly random points throughout the day
- Sometimes you feel the desire for sex before your body responds
- You’re typically the one who initiates sex
- You seem to want to have sex more frequently than your partner
- You can feel turned on in a lot of different situations
- Feel turned on → have sex

Responsive Sex Drive

- You rarely think about sex
- Sex doesn’t sound tempting until you’re in the middle of it. Sometimes at the end of sex, you think to yourself, “That was fun. Why don’t I want that more often?”
- You rarely initiate sex
- You seem to want sex less frequently than your partner
- The situation needs to be “just right” for you to feel turned on
- Start having sex → feel turned on
- Responsive sex drive can be more common for people with chronic conditions; this may be a consistent experience or may occur during health flares

If you’re interested in learning more about spontaneous and responsive sex drives, you can [check out sex therapist Vanessa Marin’s sex drive guide](#).

Tips & Tricks

- To aid in proprioception and your sensory experience, watch yourself in the mirror.
- To aid in proprioception, reduce pain, and better understand the sensations you are experiencing, rub your body parts head to toe (or toe to head - order doesn’t matter!) before and even during sex

- or have your partner do so.
- Use pillows and cushions for added stability and support; an adjustable bed frame can also be helpful.
- Work with a pelvic floor physical therapist to address pelvic floor issues (e.g., pain, instability, tightness, poor coordination, etc.).
- Learn tongue exercises to strengthen your tongue, jaw, and neck muscles (stay tuned for more information about this).
- Have a “one head up at a time” rule to avoid hitting heads, particularly if you struggle with proprioception and vision.
- Use at-home pelvic floor tools to reduce pain and increase comfort:
 - [Intimate Rose Pelvic Wand](#)
 - [Intimate Rose Dilators](#)
- Explore using toys. Note: Some (not all!) people with MCAS get triggered by vibration.
- Take the time to think about and discuss with your partner how you define “sex,” what your needs are, and what little things can help you feel fulfilled, even when your fatigue or pain keeps you from doing everything you want to do.
- Design a “sex menu” with your partner that includes different acts for different energy levels.
- Work with a mental health professional to address ongoing and past stressors and traumas, especially sex- and intimacy-related trauma.
- Practice mindfulness to help you stay in the moment.
- If you have POTS, have salty kisses! Keep bowls of salt near your bed and around your home, and add some salt to your kisses to help ensure you stay conscious!
- Take the time to get creative and discover positions that allow you to be more comfortable.
- Remind your partner to brush his/her teeth, particularly if they’ve recently consumed food or drinks that may trigger you to experience a mast cell reaction.
- Create a calming environment for your nervous system, and take the time to allow your body to recognize that it is safe.
- Find safe and comfortable lubricants. I like these:
 - [Bee Friendly Queen Bee Vaginal Moisturizer and Personal Lubricant](#)
 - [Slippery Stuff Personal Lubricant Gel](#)
- Take time to understand how you experience sensations, communicate about them with your partner, and develop a comfort with speaking up immediately about your needs.
- Develop a plan with your partner to alleviate or remedy uncomfortable or painful sensations and to find alternatives that either neutralize the uncomfortable sensations or actually feel good.
- Plan your eating and sex lives so as to keep at least 2 hours between the two activities to avoid or reduce discomfort associated with bloating, nausea, etc.
- Coordinate your sex life around times of day when you tend to experience fewer symptoms and less fatigue.