Sexual Health and Vulvar Disease:

A Guide to Common Concerns

Center for Vulvar Diseases



Welcome to Michigan Medicine's Center for Vulvar Diseases.

Here at Michigan Medicine, we believe sexuality (how people experience and

express sexual feelings) is an important part of life. Unfortunately, there are

many physical (body) and psychological (brain) conditions that may affect

healthy sexual functioning. It can be confusing, overwhelming, and frustrating

to deal with a condition that can make it hard for you to enjoy your sexuality.

This packet addresses some of the common sexuality topics that are important

to patients at our clinic.

If you are a patient at the Center for Vulvar Diseases, and you have questions or

concerns about your sexual health, please reach out to our team to set up a

time to talk.

Warmly,

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Table of Contents:

Sexual Response and Desire	4
Why sex is not a drive4	
Dual Control Model of Sexual Response: The	
accelerator and brakes5	
Spontaneous desire vs. responsive desire6	
Increasing sexual desire7	
Sexual Appearance	11
Your feelings about your body11	
Your partner's feelings about your body12	
Vulva diversity12	
Sexual Activity	14
I want to have sex, but it hurts!14	
Sexual intimacy without penetration15	
Getting back to being sexual16	
Sexual Health Resources	18

Sexual Response and Desire

Why sex is not a drive

You might be surprised to learn that the common term "sex drive" describes something that doesn't exist. We use it to describe an interest in sexual activity, but it is not that simple. A **biological drive** is something that exists to keep the body alive and healthy. For example, hunger is a drive. If we don't eat, our bodies will suffer and eventually die.

Sex is an **incentive motivation system**. Basically, this means sex is something that can, in the right context, make our bodies feel good. Eating a yummy dessert is example of an incentive motivation system; our bodies and brains might feel good after eating something sugary and delicious, but we do not need that specific food to stay alive.

Why is understanding sex as an incentive motivation system, rather than a drive, important?

If someone isn't experiencing a biological drive, we start to think something is wrong. For example, if someone isn't hungry for a month, even if they haven't eaten in weeks, there is probably something wrong with their bodies. However, there is nothing wrong with a well-fed person who has no interest in eating a dessert.

The point is that sex is not necessary for our bodies to survive. No one has died from not having sex. If we keeping saying that sex is a drive, many people will think there is something wrong with their bodies if they do not experience **sexual desire** (the feeling of wanting to have sex). There are lots of understandable reasons to not experience sexual desire, including a person's **physiology** (the way their body functions). Just like there are reasons to say

"yes" or "no" to dessert, there are reasons to have or not have interest in sexual activity.

Dual Control Model of Sexual Response: The accelerator and brakes

We can think about sexual desire as a 2-part system, connected to our brain and body responses. This is called the **Dual Control Model of Sexual Response**. The 2 parts are the **sexual excitation system** and the **sexual inhibition system**. These systems act very similarly to the brakes and accelerator (gas pedal) of a car. If you press a car's accelerator, it tells the car to go, and if you press the brakes, it tells the car to stop. Think of the sexual excitation system as our sexual accelerator, and the sexual inhibition system as our sexual brake. Both are important for healthy sexual functioning.

Sexual excitation system, or sexual accelerator

When we think about or experience something that is sexually interesting, our sexual accelerator gets pressed (our sexual excitation system turns on). When our accelerator is pressed, we sometimes feel physically aroused and have sexual desire. Some signs of physical arousal include increased heart rate and blood pressure, increased blood flow to the **genitals** (sex organs, or your "private parts") which makes them more sensitive to touch, and increased vaginal wetness.

Our sexual accelerators can be pressed by anything related to sex and any reason you might want to have sexual activity. Examples of sexual accelerators could include:

- Your partner looks particularly attractive
- You've read or watched something erotically charged
- You feel confident
- Your partner kissed you in just the right way
- You want to have an orgasm

• You want to get pregnant

Anything related to sexuality might press your accelerator, even if you don't find it enjoyable. For example, maybe you don't like a friend's sexual joke, but your body starts to feel aroused. This is a normal response.

Sexual inhibition system, or sexual brakes

When we think about or experience something that lowers our sexual interest, our sexual brakes get pressed (our sexual inhibition system gets turns on). Our sexual brakes can be pressed by any reason you might want to avoid sexual activity. Examples of things that could press our sexual brakes include:

- Stress (this is the most common sexual brake)
- Fear of pregnancy or sexually transmitted infections (STIs)
- You're in the middle of a work meeting
- Exhaustion (feeling really tired)
- Pain
- Feeling tired of being touched (being "touched out")
- Your partner has bad breath
- Your relationship with your partner isn't safe or happy
- You don't like how your body looks

Sexual brakes have a strong influence on our sexuality. In fact, most problems with sexual desire are caused by too much pressure on our sexual brakes. Think about driving a car: no matter how hard you press the accelerator, if the brake is on, the car isn't going anywhere.

Spontaneous desire vs. responsive desire

Sexual desire can be both **spontaneous** and **responsive**.

Spontaneous desire is sexual desire that seems to come out of nowhere, or with little effort. It is getting excited and motivated for sexual activity with little or no difficulty. This is the main form of desire that we see in the media (TV,

movies, books, etc.). Romance novels and romantic comedies depend on this form of desire to keep plots moving.

Responsive desire is less represented in the media, but it is actually the most common way many experience sexual desire. Responsive desire is desire that comes after some kind of pleasing situation or feeling. You can have responsive desire from physical, emotional, and/or social experiences. Many experience desire only after their bodies have become physically aroused. Many others find themselves having desire for sexual connection after they feel emotionally connected to their partners. Some examples of responsive desire include:

- You and your partner spend a few minutes kissing, and you find yourself wanting more
- You see your partner taking care of your children in a warm and loving way, and you find yourself wanting to have sex with them
- You and your partner watch a movie with attractive actors while you're cuddling on the couch, and you start to feel desire
- You read an erotic (sexy) story, and you feel the urge to be sexual with your partner

Increasing sexual desire

If you are feeling low sexual desire and you'd like to increase your desire, here are a few suggestions. Increasing desire can be complex and complicated, so you may find these helpful, but you might not. We highly recommend the books *Come As You Are* by Emily Nagoski and *Better Sex Through Mindfulness* by Lori Brotto for more detailed information on this subject. We also recommend the Netflix series, "The Principles of Pleasure."

Reducing sexual brakes

To increase desire, many people think that they need to do things to press on their sexual accelerator more (like wear lingerie, read erotica, etc.). While pressing on the sexual accelerator can help, you usually need to focus more on ways to reduce pressure on your sexual brakes. If our sexual brakes are on, it will be very hard to experience desire.

Take a moment to think about what might be pressing on your brakes.

- What is your stress level?
- What is the quality of your relationship?
- Are you getting enough sleep?

Think about what you could do take some pressure off your brakes.

- Do you need more help with household chores?
- Do you need time away from caregiving?
- Do you need a relaxing bath or shower?
- Do you need something to prevent pregnancy or sexually transmitted infections?
- Do you and your partner need to improve the quality of the relationship?
- Are you in pain?

Many of the patients at the Center for Vulvar Diseases experience significant vulvar and vaginal pain. Pain, while bad enough on its own, also comes with the fear of more pain. Both pain and the fear of pain can put a lot of pressure on sexual brakes. For this, we recommend lots of self-compassion and patience. Be kind to yourself. Go slow with sexual activity.

• If you have pain during sexual activity, stop doing what you're doing and focus on another form of **sexual intimacy** (feeling close to or connected with someone in a sexual way). For example, if **vaginal penetration** (having a penis, finger, or sex toy inserted into your vagina) becomes painful, switch to some other kind of touch.

- Discomfort is okay to tolerate, but pain is not. Again, if you experience
 pain, stop the activity. "Pushing through pain" will only make your fear
 and anxiety worse. Do not push through pain!
- By slowly starting to have nonpainful sexual contact, your body will start to relearn sexual activity as a source of pleasure. This takes time. Be patient with your body. Sometimes you have to go slow to get to your goal faster.

Increasing sexual accelerators

Perhaps you don't have a lot pressure on your sexual brakes, but you need more sexual accelerators. If that's the case, here are a few suggestions:

- Start a mindfulness practice that involves more awareness of the genitals and breasts. Many patients with vulvas become disconnected from feelings of physical arousal. It may help to learn to pay attention and be aware of your body's feelings of arousal and pleasure. *Better Sex Through Mindfulness* by Lori Brotto is a good book about this. You can also find guided mindfulness mediations at www.loribrotto.com/mindfulness-recordings.
- Erotica (sexy books, audiobooks, photographs, or videos) can cause
 physical arousal for many people. If you are comfortable, check out some
 erotica and notice how the arousal feels in your body. Let yourself
 explore those feelings.
- Try **fantasy** (thinking about or imagining something sexual). Imagine different sexual situations. See where your imagination takes you and how it feels in your body.
 - Remember, fantasy is very different than reality. Just because you
 might enjoy the fantasy of an activity doesn't mean you have the
 desire to bring it into reality. For example, fantasies of
 nonconsensual sexual activity (sex that someone didn't willingly
 agree to) are extremely common. This doesn't mean that the person

having the fantasy actually wants nonconsensual touch. So let yourself fantasize about whatever you'd like, without judgments or shame.

Sexual Appearance

Your feelings about your body

Many of us worry that our genitals don't look normal. We feel insecure (not confident, or nervous) about how our bodies look and what others will think. This is very common. It can be helpful to remember that diversity is normal. No two genitals are going to look exactly alike.

For example, vulvas can be many colors including red, black, brown, and pink. It is very common for **labia** (the folds of tissue around your vagina) to be asymmetrical (not the same size). Some people have very large, full labia and others have smaller, thinner labia. Remember, your body is unique to you. No one else is going to look exactly like you. Your body, just as it is, deserves respect, compassion, and love.

Conditions seen in the Center for Vulvar Diseases can sometimes cause changes to your vulva's shape or appearance (how it looks). These may be small or large changes. It okay to have difficult feelings about these changes. Many find it helpful to grieve (have feelings of loss) after their body changes. However, it is important to remember that even though a medical condition may have changed your appearance, it has not changed your worth as a person. You and your physical body still deserve respect, compassion, and love.

How you think about your vulva matters. The messages you tell yourself about your vulva and how it looks can affect you. You can create your own distress or empowerment based on the thoughts you have about your body. For example, if you think "My body is deformed and ugly," you might feel sad, mad, embarrassed, and ashamed. However, if you change this thinking ("flip the script") and let yourself think, "My body is whole and healing," you will more

likely feel strong and confident. So much of what we are comes from our thoughts. We control our thoughts - they do not control us. Remember to be kind to yourself.

"Never forget that you have every right to have a satisfying sex life." - Dr. Ruth Westheimer

Your partner's feelings about your body

Many patients tell us they feel scared about how their partners will react to how their genitals look. Several research studies have tested reactions to vulvar appearance, and the results consistently show that it's not a big deal. Partners said that how a vulva looks doesn't affect their sexual desire or pleasure. Most study participants didn't have strong preferences for how they wanted a vulva to look.

In a healthy relationship, partners will care more about both having a satisfying sexual experience than the appearance of their genitals. If you find yourself with a partner who does not respect and appreciate your body, it may be time to look closely at how healthy that relationship is.

Vulva diversity

For images of different vulvas, check out the following resources:

Betty Dodson's vulva illustrations: www.scarleteen.com/resource/advice/betty_dodsons_vulva_ill ustrations
The Great Wall of Vulva: www.thegreatwallofvulva.com

Laura Dodsworth's photography book <i>Womanhood</i> : www.lauradodsworth.com/womanhood
Women's Health Victoria: whv.org.au/resources/whv-publications/labia-library
Hilde Atalata's colorful illustrations: www.hildeatalanta.com/thevulvagallery

Sexual Activity

I want to have sex, but it hurts!

Many patients at our clinic want to be able to sexually connect with their partners, but pain is preventing them. Along with following the treatment plan prescribed by your doctor, we recommend trying the following things to reduce your sexual discomfort:

- Communicate with your partner. Plan out how you want to sexually connect and what you want to do. Go slow, and have something else you can do if pain starts to prevent you from experiencing pleasure.
- Don't focus only on penetration. There are many ways to have sex that do not involve penetration.
- Pee (empty your bladder) before and after sexual activity
- Remember that "foreplay is core play." This means that **foreplay**, or what you do before you have sex, is very important. Give your body plenty of time to become aroused before directly touching the vulva or penetrating the vagina.
- Always use a high-quality lubricant, or lube, during sexual activity. Our clinic recommends silicone-based lubricants such as Uberlube®, System Jo-Premium®, and Sliquid Silver® (just don't use a silicone lubricant with a silicone toy or dilator, as it will change the toy or dilator's texture). Some healthy water-based lubricants are also available. These include Sliquid H2O®, Good Clean Love®, and Ah! Yes® water-based lubricant. You can read the patient handout "Improving Sexual Health: Vaginal Lubricants, Moisturizers, Dilators & Counseling" for more information. Scan the QR code for this resource.
- If you feel any pain or burning after sexual activity, use ice packs (wrapped in a towel or cloth).

- After sexual activity, you can put lubricant or petroleum jelly that has been cooled in the refrigerator on your vulva.
- Dilator therapy may help increase the size of your vaginal opening.

 Please see the patient handouts "Improving Sexual

 Health: Vaginal Lubricants, Moisturizers, Dilators &

 Counseling" and "General Dilator Instructions" for more information. Scan the QR code for the dilator instruction resource.
- If you experience pain with deep penetration, we recommend the Ohnut®. This is a device worn by partners with a penis to limit how deep they can penetrate. This product has a very high patient satisfaction rating. You can find the Ohnut® available for purchase here: ohnut.co
- Try different sexual positions.
 - Positions that avoid friction (rubbing) against the vulva can be helpful, such as rear-entry (penetration from behind) positions.
 - Try a "spooning" position, where your partner penetrates the vulva from behind you while you both lie on your sides. This position also encourages slower thrusting.
 - Try a "modified missionary" position, where the person being penetrated lies on their back with a pillow under their pelvis.

"Erotic intimacy is the sharing of sexual wishes, dreams, and fantasies. It is not a matter of performance, but of self-knowledge, self-affirmation, trust, and intimacy." - Peggy Kleinplatz

Sexual intimacy without penetration

There's a common but false idea that "having sex" means having penis-invagina penetration. That's only one way to have sex! **Sex** is any activity which causes arousal and pleasure. This can be done without penetration, erections, or orgasms. Here are some ideas of how to connect sexually without penetration:

- Try some good old-fashioned kissing! Kiss from head to toe, and everywhere in between
- Oral sex (touching genitals with the mouth, lips, or tongue)
- Mutual masturbation (each partner touches themselves sexually while they're in the same space as their partner)
- Shower together
- Try a sexy massage, using different lubricants and massage oils
- Lie down together or cuddle naked
- Read or watch erotica together
- Add in sex toys to create new sensations (feelings). Try using vibrators, feathers, whips, blindfolds, or anything that sounds fun to you and your partner
- Share your fantasies with each other

There are endless ways to connect sexually. Use your imagination and lean into the possibilities.

"Sex is not about your genitals, it's about creating a context that allows your brain to interpret any sensation as sexy." - Emily Nagoski

Getting back to being sexual

Many of our patients tell us that they have not been sexual in months or years, but they would like to be sexual now or in the future. It is possible to have a satisfying sexual relationship after a short or long pause in **sexual intimacy** (being sexually close to someone). Here are a few tips to get you back to where you want to be:

- Get to know your body again. Our bodies change over time. What used to give you pleasure might not be enjoyable anymore. You might find new sensations or ways of experiencing touch that are deeply satisfying.
- Communication is extremely important. Talk with your partner or partners about what you want to do, what you'd like to experience, and what you'd like to avoid. Explore what they might want to experience as well.
- Make a plan! Good sex usually doesn't just happen. It takes time and planning. Find a time where you can connect, create desire, and enjoy the experience.
- Try sensate focus. This the most popular sex therapy exercise for helping people connect with their sexuality.
 - Sex therapy is a form of talk therapy used by mental health therapists who are specially trained in sexual health concerns.
 - Sensate focus is a series of mindfulness exercises intended to create sensual awareness. You can do this by yourself or with a partner. You can find instructions for this online using this link and QR code:
 health.cornell.edu/sites/health/files/pdf-library/sensate-focus.pdf
- Go slow! Good sex takes time. Give your brain and body all the time they need to feel safe and excited. Enjoy the sensations and experience. Let satisfaction, connection, and intimacy be your goals.
- Remember: have fun and focus on pleasure.

Sexual Health Resources

If you need more help or information, here are some of our favorite sexual health resources:

Books

- Come As You Are by Emily Nagoski
- When Sex Hurts by Andrew T. Goldstein, Caroline F. Pukall, and Irwin Goldstein
- Better Sex Through Mindfulness by Lori Brotto
- *Becoming Cliterate* by Laurie Mintz
- The Sexual Healing Journey by Wendy Maltz
- *Sex Matters for Women* by Sallie Foley
- So Tell Me About the Last Time You Had Sex by Ian Kerner
- *Mating in Captivity* by Ester Perel
- Becoming Orgasmic by Julie Heiman
- *Hold Me Tight* by Sue Johnson
- Tell Me What You Want by Justin Lehmiller
- *Magnificent Sex: Lessons from Extraordinary Lovers* by A. Dana Menard and Peggy J. Kleinplatz

Apps

- Rosy
- Emjoy
- Dipsea
- Ferly
- Coral

Videos

- "The Principles of Pleasure" on Netflix
- "The Uncomplicated Truth About Women's Sexuality" by Sarah Barmak (TEDtalk)
- "Reclaiming Female Sexual Desire" by Pamela Joy (TEDtalk)
- "The Keys to a Happier, Healthier Sex Life" by Emily Nagoski (TEDtalk)
- "<u>The Secret to Desire in a Long-term Relationship</u>" by Esther Perel (TEDtalk)

Websites

- The National Vulvodynia Association: www.nva.org
- The Vulval Pain Society: <u>vulvalpainsociety.org</u>
- Lichen Sclerosus Support Network: <u>lssupportnetwork.org</u>
- Scarleteen: www.scarleteen.com

Sex therapy

- Sex therapy at Michigan Medicine: www.uofmhealth.org/conditions-treatments/sexual-health
- American Association of Sexuality Educators, Counselors and Therapists:
 www.aasect.org

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