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# Sexual Function in Females with Spina Bifida

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# Overview

- Sexuality and sexual activity in women with spina bifida
- Special considerations in addressing sexual health
- Sexual satisfaction?
- Family planning



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# SEXUALITY AND SEXUAL ACTIVITY

# Sexual Identity and Orientation

- Online international survey of 119 women
  - Sexual Identity:
    - 99% of women identified as female
  - Sexual Orientation:
    - 85% heterosexual (lower than general population)
    - 3% homosexual
    - 10% bisexual (higher than general population)
    - 1% asexual
    - 2% other

# Who is sexually active?

- Older<sup>1</sup>
  - Mean age: 17<sup>2</sup>
- Lower level of lesion<sup>1,3</sup>
- Continent<sup>1</sup>
  - Or no difference?<sup>3</sup>
- No hydrocephalus<sup>4</sup>
- Live independently<sup>3</sup>

1. Gatti C et al, J Urol 2009
2. Sawyer SM and Roberts KV, Deve Child Nuerol 1999
3. Lassmann J et al, J urol 2007
4. Cardenas DD et al, Arch Phys Med Rehabil 2008

# But...

- There are sexually active women with spina bifida who are younger, have high levels of lesion, are incontinent, have hydrocephalus, and who do not live independently<sup>1</sup>
- 90% would like to get married, 76% would like to have children<sup>2</sup>
- 5% of women have talked to a doctor about sex<sup>3</sup>
- 74% of youths with SB rate their knowledge of sexual health and SB as “poor” or “extremely poor”<sup>2</sup>
  - “Can I pass SB on to my partners by having sex with them?”

## **EVERYONE needs education**

1. Lassmann J et al, J urol 2007
2. Sawyer SM and Roberts KV, Deve Child Nuerol 1999
3. Gatti C et al, J Urol 2009



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# SPECIAL CONSIDERATIONS



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Some basics



# Precocious Puberty

- 15% by age 8
- Hydrocephalus increases risk

...I remember the first time I had my period [at age 8]... I thought I was bleeding to death.

36 year old female

# Other basics

- Lubrication
  - Some women do not excrete vaginal lubrication
- 4-5 *mg* of folic acid daily
  - Requires a prescription
- Contraception
  - No latex condoms!
  - Seizure medications may decrease efficacy of oral contraceptives
    - Also increased risk of birth defects with certain seizure medications



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# Incontinence

# Urinary Incontinence During Sex

I'm constantly worried about the incontinence happening. I'm always worried that I'm going to get distracted [during sex] in worrying about that too much.

35 year old female

# Urinary Incontinence During Sex

If he's touching my stomach I have to worry about the urostomy pouch, is it gonna leak or become disconnected?

52 year old female

# Urinary Incontinence During Sex

I sometimes urinate  
when I orgasm.

22 year old female

# Urinary Incontinence During Sex: Recommendations

- Empty bladder/urostomy bag before sex
  - Decreases spontaneity
  - Incontinence still may happen
- Use mattress protectors
- Place chucks pads under sheets to be discrete
- Warn partner before

# Fecal Incontinence During Sex

Even though I have control over my bowels, sometimes during sex I don't.

52 year old female



# Fecal Incontinence During Sex

The bowel– there's really nothing I can do about that because it seems to have a mind of its own so I just pray.

35 year old female

# Fecal Incontinence During Sex: Recommendations

- Watch diet before sexual activity
- Empty bowels before sex
  - Especially if anal penetration
- Mattress protector
- Wipes
- Warn partner before



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# Positioning

# Positioning

Judging by how I'm  
feeling that day I'm like  
this position is a yes or a  
no.

32 year old female

# Positioning

- Considerations:
  - Scoliosis
  - Back pain
  - Hip pain or instability
  - Limited mobility
  - Limited ability to bend
  - Osteoporosis
  - Weight gain
  - Pelvic organ prolapse

# Positioning

- Be aware of limitations
- Avoid any painful position
  - Inform partner if hurting
- Different positions may be better different days
- Consider using assistive devices
- Seek advice of a physical therapist or other expert

# Positioning: General

Mostly it's been missionary.  
Laying on my stomach is good.

35 year old female

This show ain't gonna happen  
with me standing up.

29 year old female

# Positioning: Pelvic Organ Prolapse

Sex used to really hurt... until I started doing it what they call “doggy style”... That’s how my gynecologist explained it after looking at my anatomy... I have [pelvic organ] prolapse.

27 year old female



## Positioning: After Weight Gain

When I was younger I was smaller but now I'm heavier so I really don't feel comfortable being on top of somebody. I like side by side... scooting all the way to the edge of the bed for the woman is another good position.

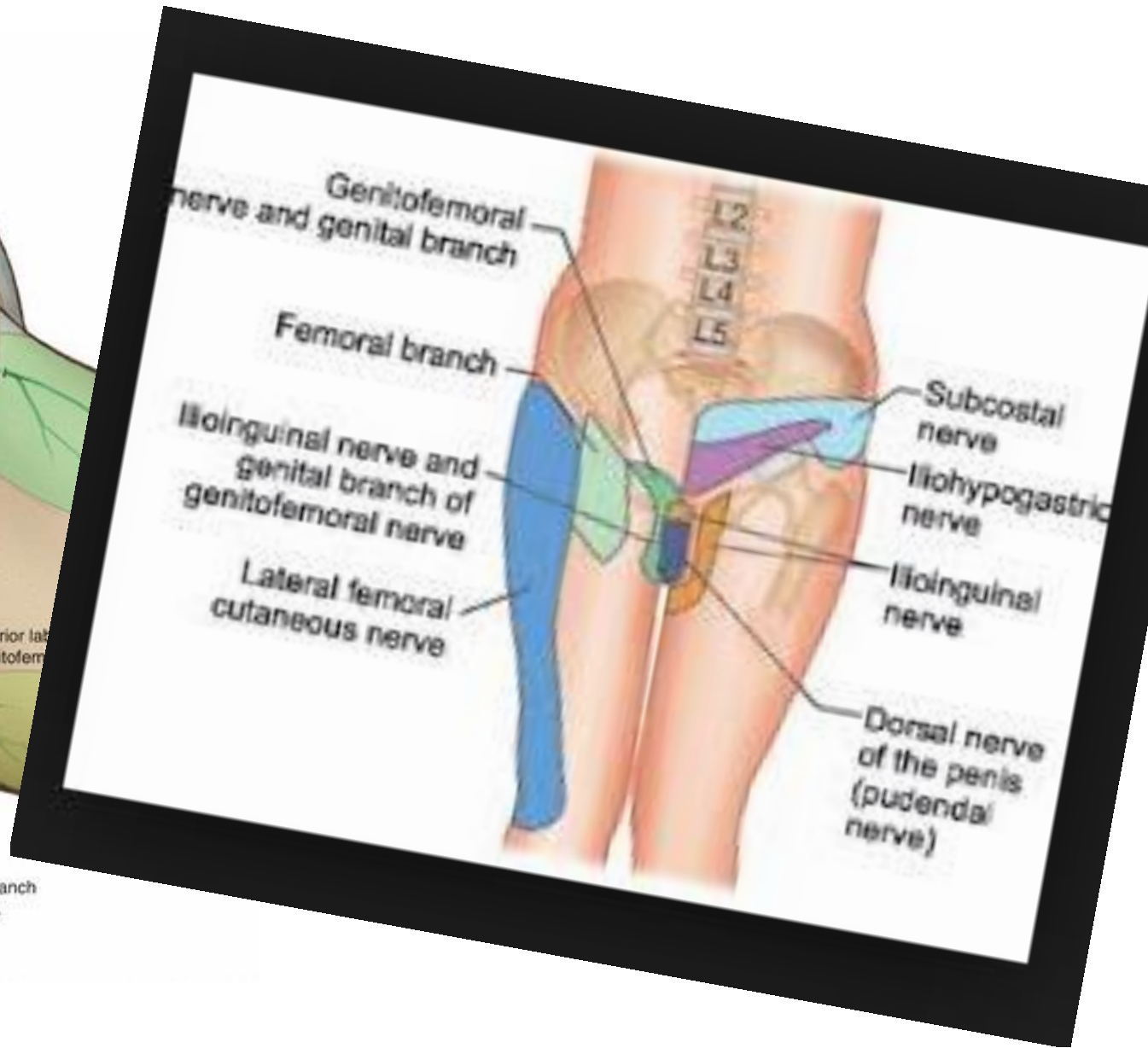
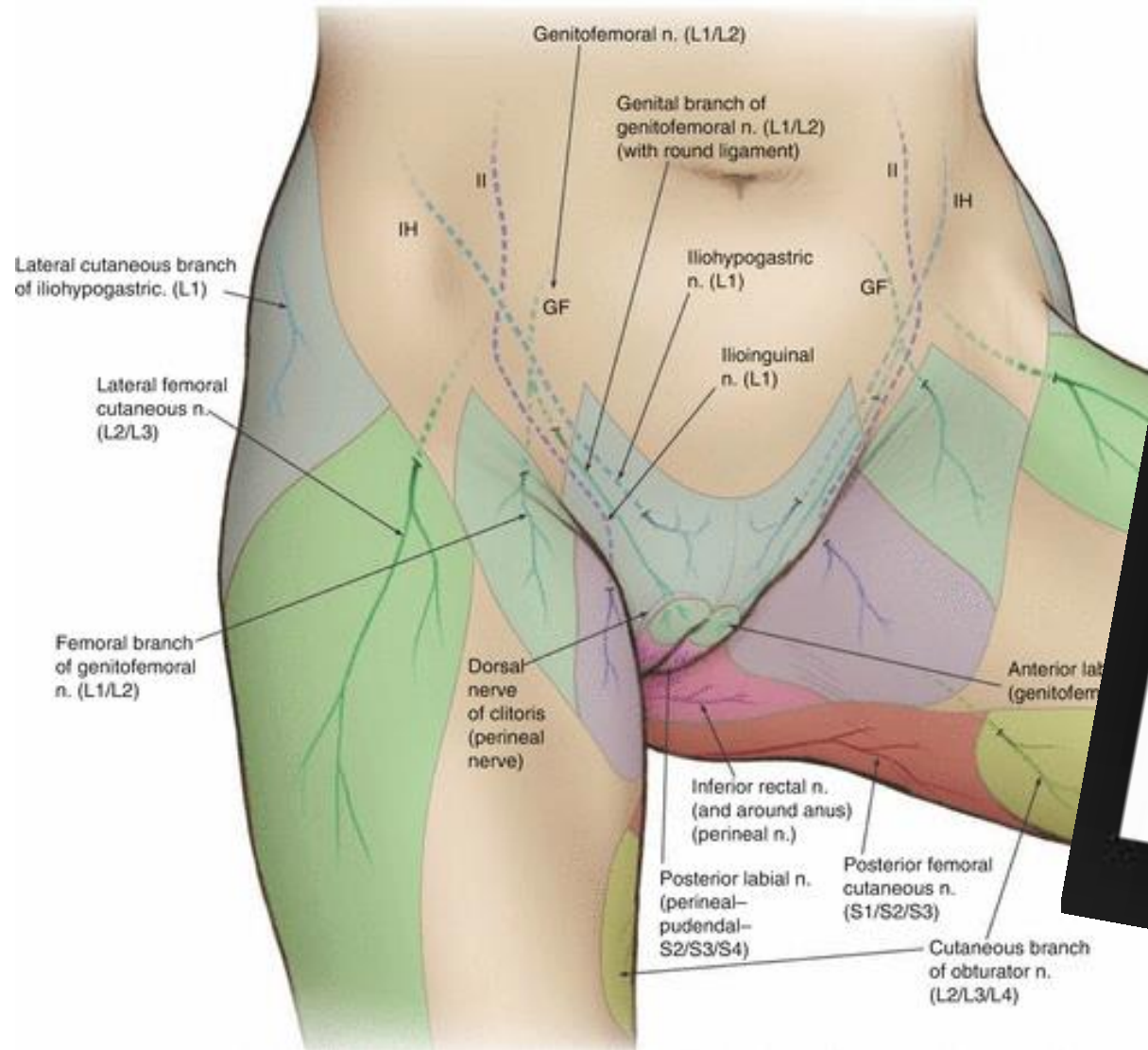
52 year old female



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# Sensation

# Nerve innervation



# Sexual Sensation

- 80% of women have some genital sensation
  - Rare if lesion above L2
- 37% of women experienced an orgasm

# Sexual Sensation

I can feel and everything but  
it's like certain parts of my...  
private area like I don't feel  
it 100%.

24 year old female

# Sexual Sensation

...if I'm walking a lot or if I'm sitting for a long period of time, then I'll have more numbness than usual and then obviously I don't enjoy it.

24 year old female

# Sexual Sensations: Recommendations

- Experiment
- Map out sensation and inform partner
  - Often increased above level of lesion

# Sexual Sensation: Recommendations

For me with spina bifida I think that anal sex is how I get off versus vaginal. I guess anal and oral.

27 year old female



# Sexual Sensation: Recommendations

And hey, if you can't orgasm, at least you can make yourself feel good.

22 year old female



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# Sexual Satisfaction

# How satisfied are women?

- Limitations:
  - No validated survey instruments for women with spina bifida
  - Small populations studied
  - Nuances hard to elucidate from surveys
  - Results may vary by:
    - Most recent experience
    - Current partner (supportive vs. not)
    - Opportunities
    - Confidence

# How satisfied are women?

- Studies do suggest women may have some sexual dysfunction

1. Lassman J et al, J Urol 2007
2. Gamé X et al, J Pediatr Urol 2014
3. Von Linstow et al, J Rehab Med 2014
4. Lee NG et al, J Pediatr Urol 2015

# Improving (Partnered) Sexual Satisfaction

- Build confidence
  - Affirming partner
- Selectively choose a partner
- Give feedback
  - Seek satisfaction for both
- Seek advice and counseling

## Sexual Sensation: Affirming Partner

When I first met my husband I up front said I have a lot of medical issues, he said I don't care. And then the relationship started to go into more of an intimate level and I said I have to tell you things are not "normal." And he just looked at me and said we'll figure it out.

36 year old female

# Sexual Sensation: Give Feedback

I genuinely believe that I have a better sex life than most of my friends because I have to communicate what I need during sex...

29 year old female

## Sexual Sensation: Seek Advice

At one point I actually went and I saw a physical therapist who gave me a position. It would have been helpful much earlier in my life.

30 year old female





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# FAMILY PLANNING (Briefly)

# Family Planning

- The number of women with SB having babies is increasing! However...
- Too many providers assume:
  - Women are not sexually active
  - Women cannot have babies
  - Women should not be mothers
- As a result:
  - Few women use birth control
  - Many think they cannot get pregnant
  - Women have unintended pregnancies
  - Women have difficulty accessing information and finding supportive providers

# Family Planning

- Having babies is very important to most women with spina bifida
- Fertility is normal for most
- Important to discuss the possibility of becoming pregnant with women starting in adolescence
  - Also offer contraception

# Interest in Having a Family

I've always, always wanted to be a mother ever since I was little.

27 year old female

# Family Planning

- Many adolescent and adult women with spina bifida are unaware they can become pregnant<sup>1</sup>
  - Assume they cannot because of their spina bifida
  - Providers tell them they cannot
- Unintended pregnancies occur in this population!
  - 3 women in a study of SB youths ages 14-23<sup>2</sup>
  - 5/25 women in a study of SB women<sup>1</sup>
    - 5/6 of pregnancies in this study
- Women value provider's willingness to help them reach their sexual and reproductive health goals over their experience and expertise in the area<sup>1</sup>

1. Streur CS et al, Disabil Health 2019

2. Sawyer SM and Roberts KV, Deve Child Nuerol 1999

# Misinformation From Providers

Medical doctors looked at me for years and always told me that I would never bear a child, ever.

27 year old female

Unintended pregnancy at age 18

# Conclusion

- Women with SB have sex and babies
  - Even if not currently sexually active, majority interested in having a partner and having babies one day
- Addressing sexual and reproductive health for these women can:
  - Improve their sexual satisfaction
  - Promote positive relationships
  - Reinforce their identity as sexual beings
  - Help women dream and plan for the future
  - Prevent unintended pregnancies
- You don't need to be an expert to start talking!

Thank you!

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