



SPINA BIFIDA
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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?

- Older¹
 - Mean age: 17²
- Lower level of lesion^{1,3}
- Continent¹
 - Or no difference?³
- No hydrocephalus⁴
- Live independently³

1. Gatti C et al, J Urol 2009
2. Sawyer SM and Roberts KV, Dev Child Neurol 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 independently¹
- 90% would like to get married, 76% would like to have children²
- 5% of women have talked to a doctor about sex³
- 74% of youths with SB rate their knowledge of sexual health and SB as “poor” or “extremely poor”²
 - “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.

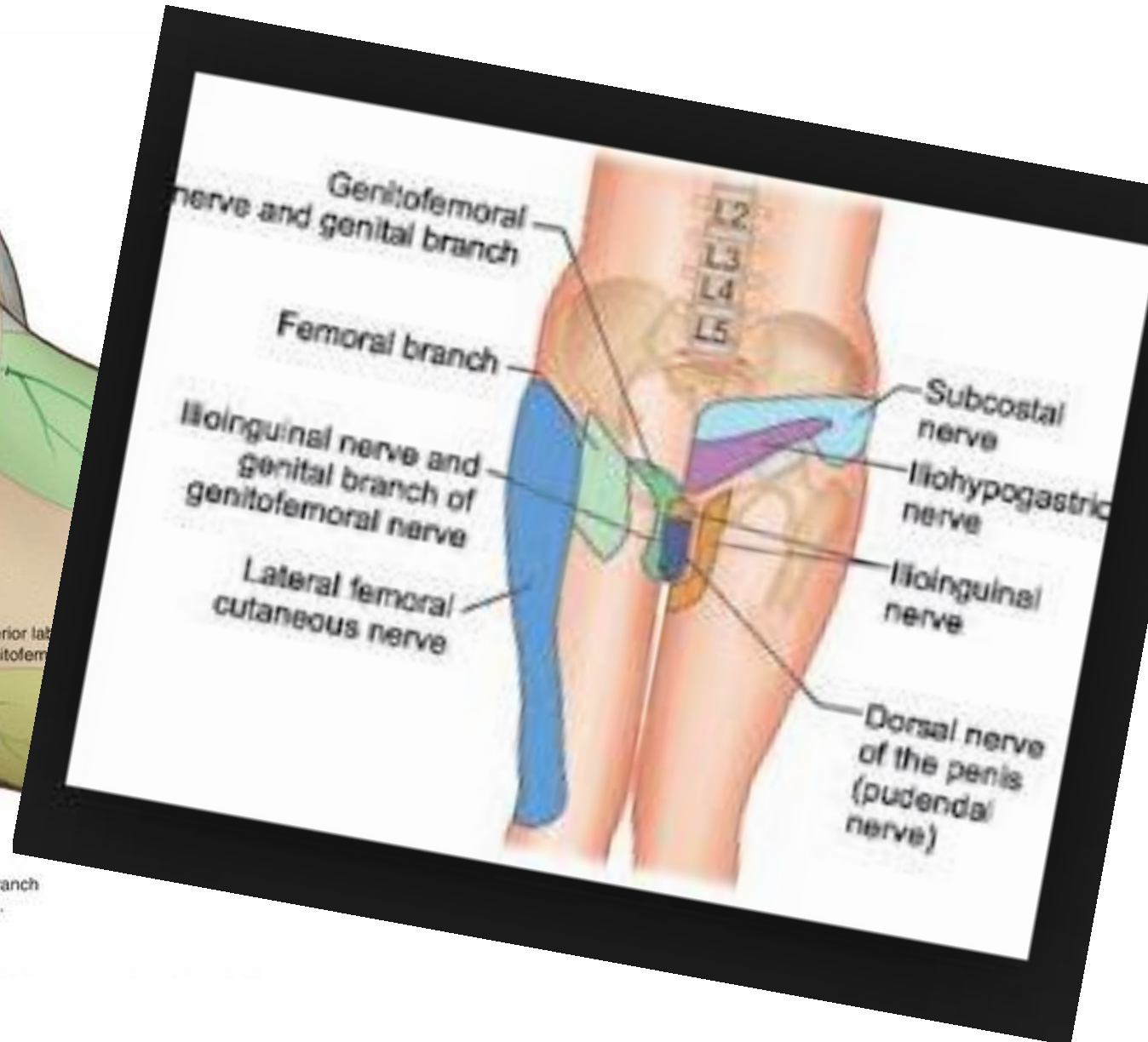
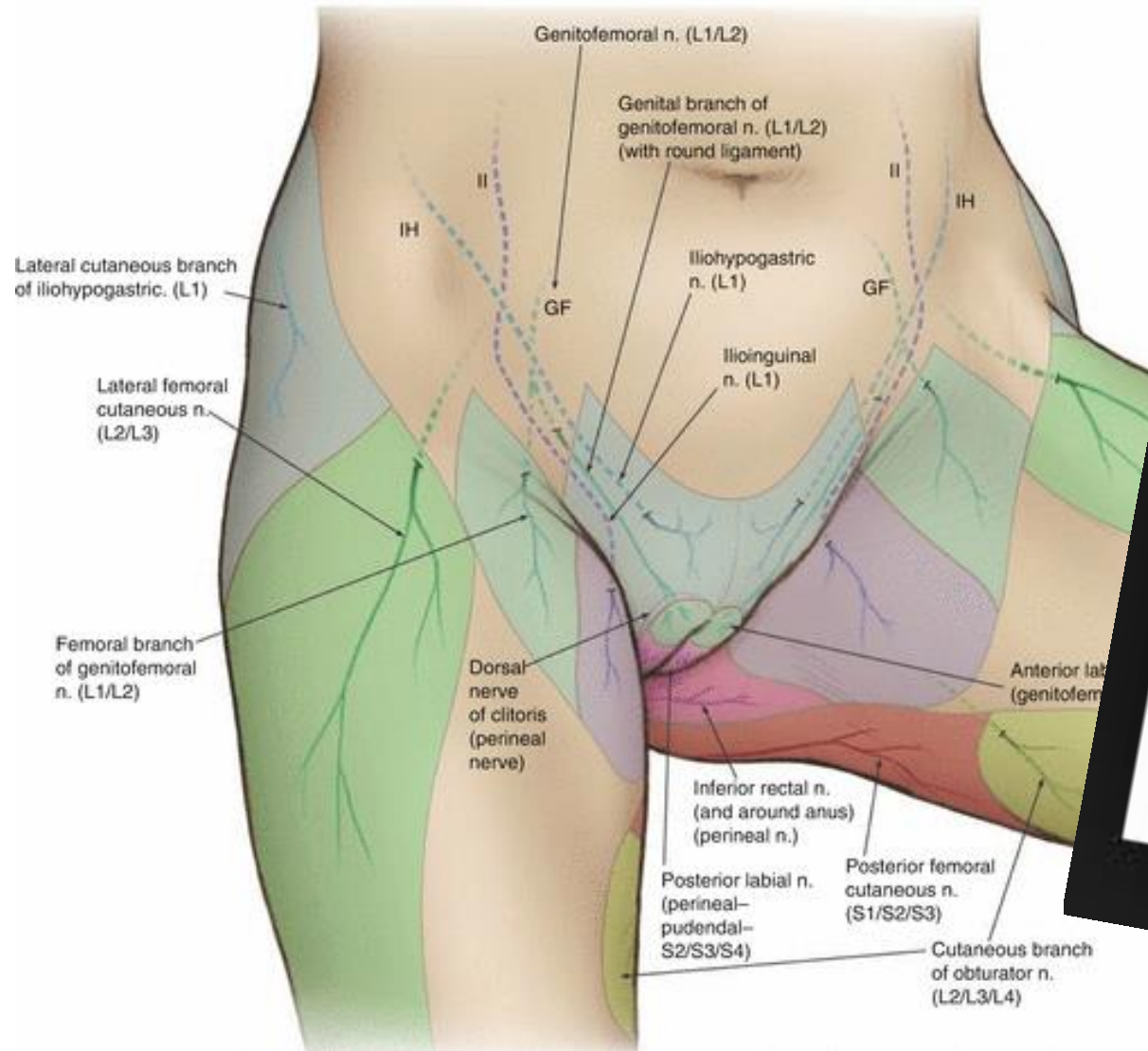
52 year old female



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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 pregnant¹
 - 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 14-23²
 - 5/25 women in a study of SB women¹
 - 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 area¹

1. Streur CS et al, Disabil Health 2019

2. Sawyer SM and Roberts KV, Dev Child Neurol 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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