



SPINA BIFIDA
ASSOCIATION

*SBA Guidelines for the care of people
with Spina Bifida: Urology and Sexual
Health*

SBA Clinical Care Conference

June 29 , 2019

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Desired Outcomes of the Guidelines

Optimization of outcomes for people with Spina Bifida and Maximization of the ability of adults with Spina Bifida to participate as desired across the life span.

Empowerment of people with Spina Bifida to seek knowledge and skill-building by way of the advancement of knowledge and comfort of health care professionals to provide them with developmentally appropriate and accurate health education.

*Found online: <https://www.spinabifidaassociation.org/resource/sexual-health/>
Urology & Sexual Health, pages 148-76*

Sexual Health

- As stated by the World Health Organization, “Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as to the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence.”

World Health Organization. Defining sexual health. Sexual and Reproductive Health 2006; http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/.

World Health Organization. International Classification of Functioning, Disability and Health Browser.2015 <http://appswho.int/classifications/icfbrowser/>

Review of the literature re: SB & sexuality

- varying levels of satisfaction with their sex lives, with approximately half reporting dissatisfaction with their sex lives.
- Sexual satisfaction and intimacy are directly related to quality of life, but they are rarely studied.
- Sexual activity in people with Spina Bifida is delayed.
- People with the lowest lesion levels had the highest chance of finding a partner and engaging in sexual activity.
- Lower lesion levels are associated with sexual satisfaction.

Research findings, continued

- In general, having hydrocephalus was predictive of having more problems with sexual function and relationships.
- Urinary incontinence was associated with altered sexual functioning in multiple studies, but not all.
- Bowel and bladder incontinence has been demonstrated to interfere with sexual activity, such that continence enhances sexual functioning.
- As may be expected, restored penile sensation is associated with improved sexual health and satisfaction.

Youth with Spina Bifida want to know about:

- romantic relationships
- sexuality
- fertility/parenthood
- more sexual education

Akre C, Light A, Polvinen J, Rich M. What young people with Spina Bifida want to know about sex and are not being told. Child Care Health and Development 2016;6:963-9.

Inadequate sexual education may explain why compared to healthy controls, people with Spina Bifida were **less likely** to use birth control when sexually active

Physical Challenges common to Spina Bifida:

- Scoliosis may make laying on your back uncomfortable especially if bearing weight of your partner
- Unable to move hips or legs
- Latex sensitivity or allergy so careful with condoms.
- Loss or Variation in skin and genital sensation
- Chance of incontinence of B & B

Beautifully & Wonderfully made

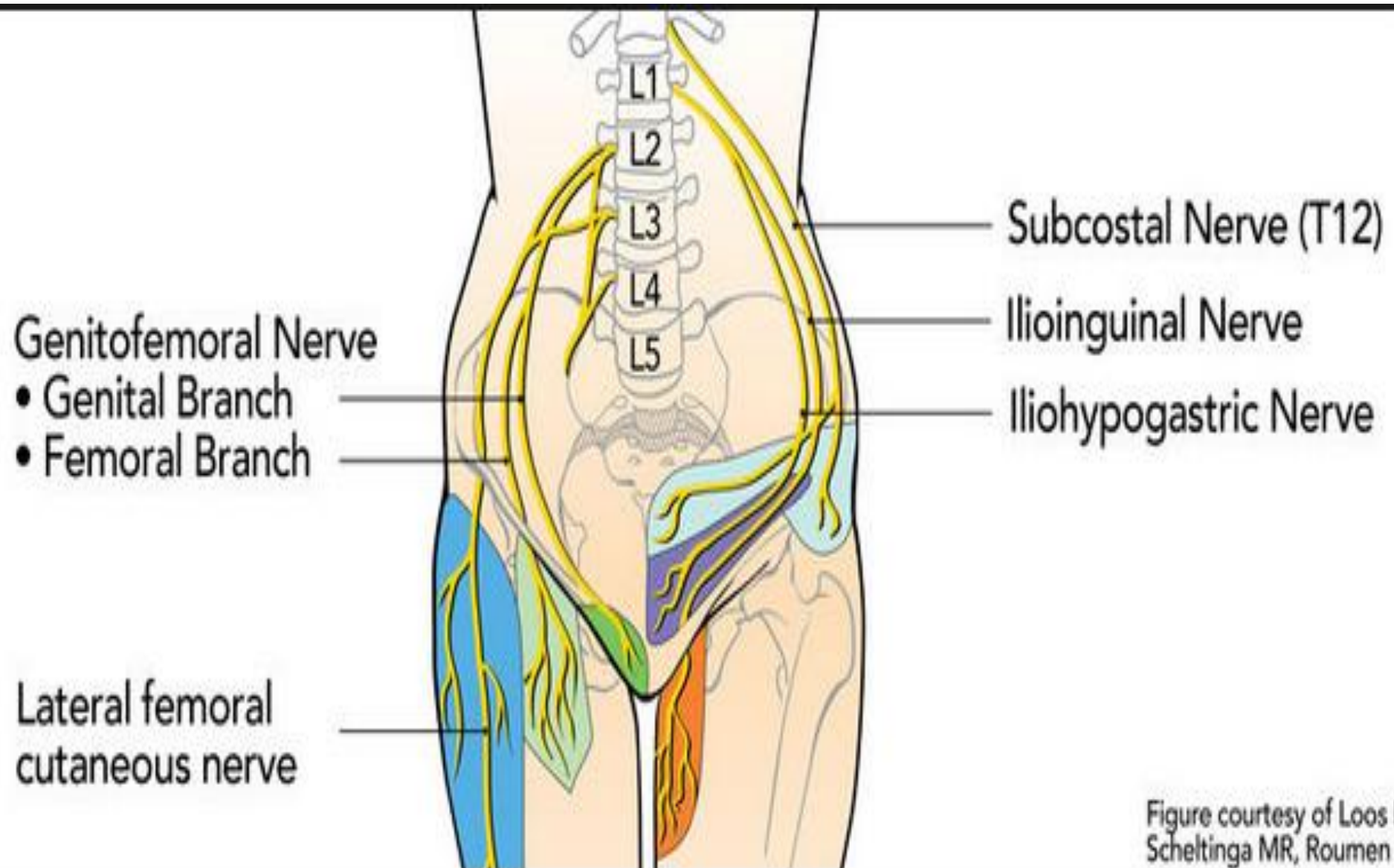
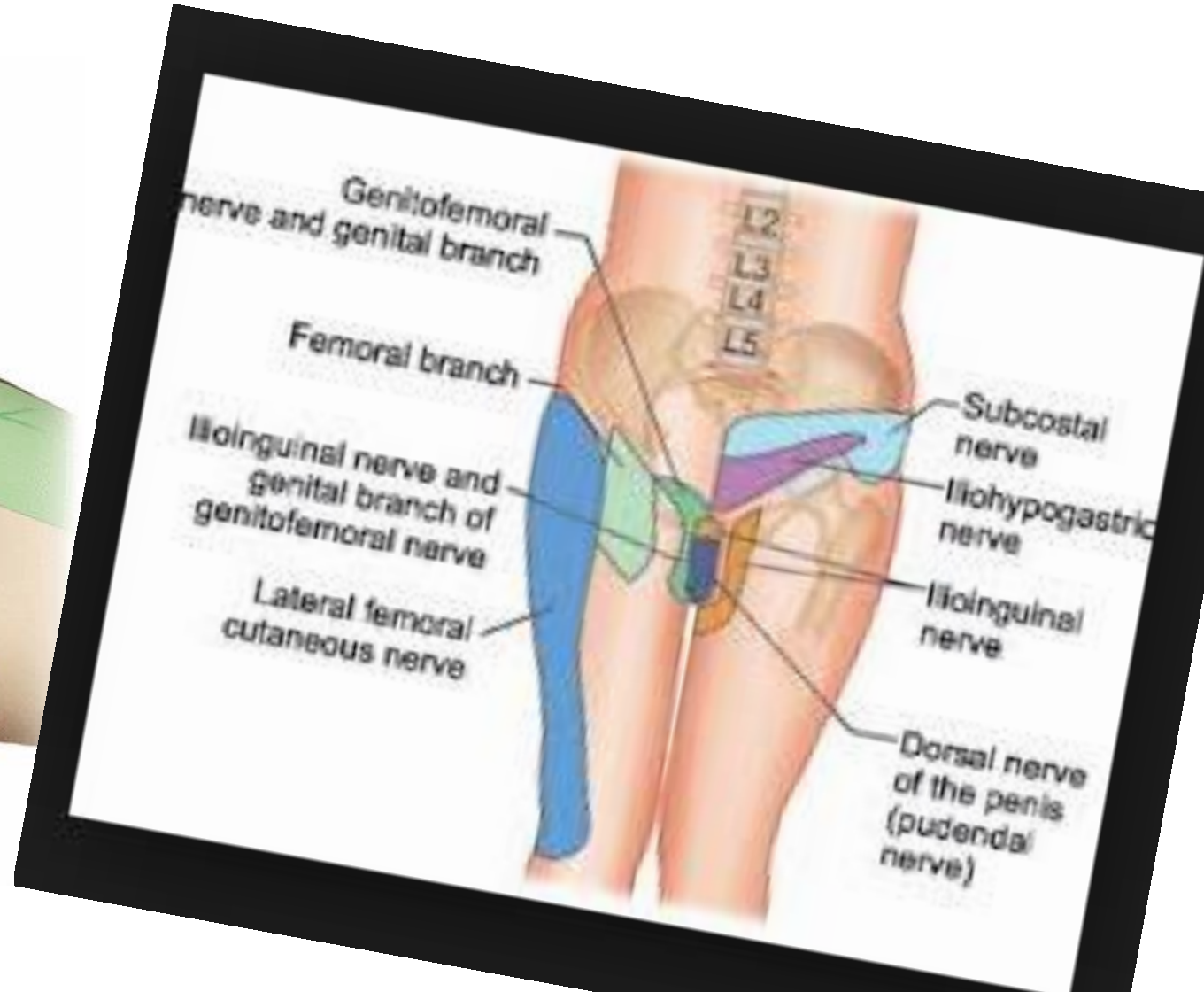
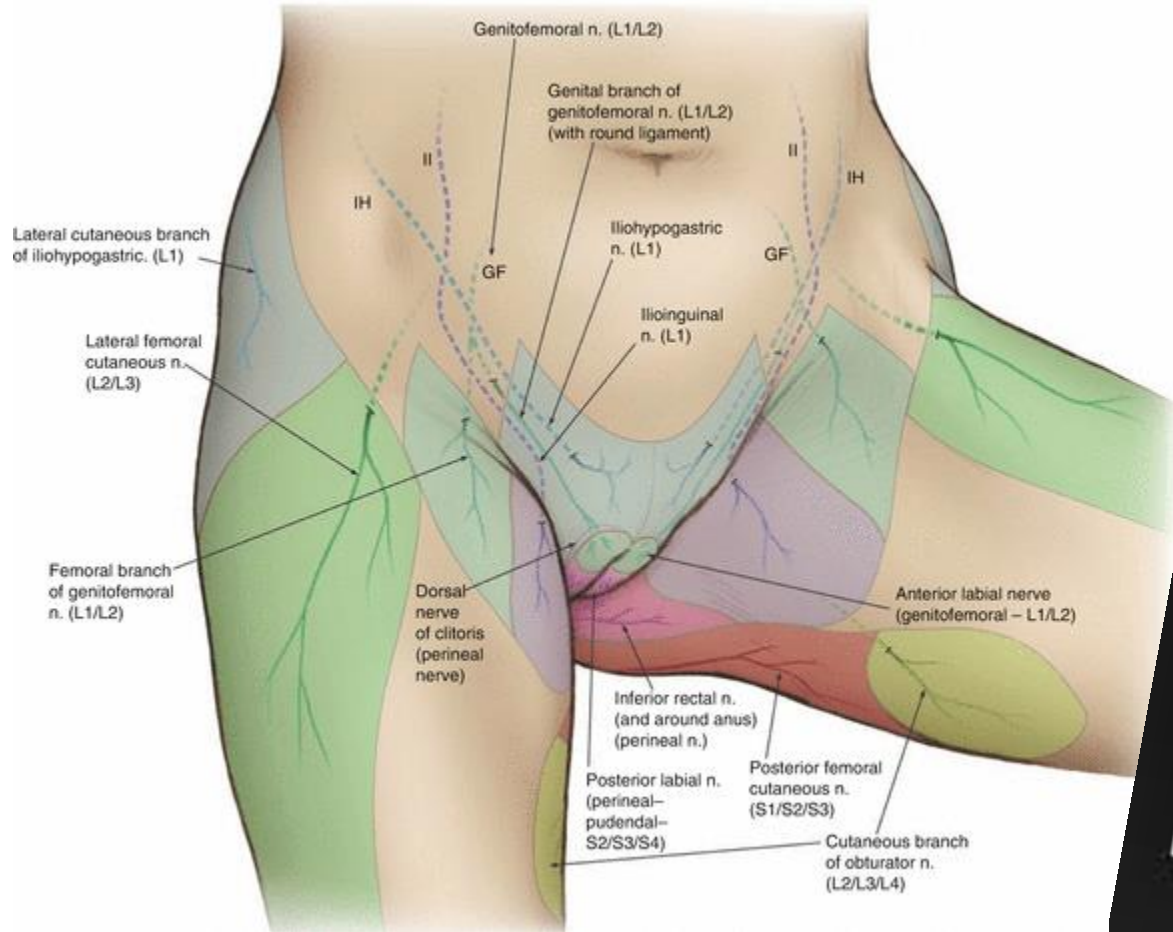


Figure courtesy of Loos M,
Scheltinga MR, Roumen RM

Nerve innervation

All the nerves and reflexes for bowel, bladder and sexual organs are in the same area.



Sex & catheterization

- For men, catheterization may stimulate an erection. When you stimulate a reflex erection, you probably are going to want to use that erection for intercourse.
- For men, what is recommended is leaving a large loop of catheter at the end of the penis, so that if the person does get an erection, there's enough catheter for the penis to climb, and then placing a condom over it.
- The nice thing is that if a person does not get a great reflex erection, so the penis doesn't get real hard, the rigidity of having the catheter run down along the side of the penis actually can help stimulate their partner.
- For women, tape the catheter out of the way on the abdomen. Remember that the *catheter* is entering the urethra, not the vagina, so it will not affect sexual activity greatly.

Impaired arousal

- **Women**

- Pain during intercourse
- Lack of vaginal lubrication
- Inability to orgasm or recognize orgasm

- **Men**

- Achieving and sustaining erections
 - Ejaculation
-
- Both experience performance anxiety that interferes with arousal over fear of failure and fear of b & b accidents

Epilepsy and AEDs on Male Sexual Health

Epilepsy occurs in 1:4 with SB.

More prevalent with myeloschisis as opposed to myelomeningocele, lipomeningocele and myelocystocele.

Seizure activity located in the temporal lobe adversely affects testicular endocrine function.

Carbamazepine, oxcarbazepine, and valproate are associated with sperm abnormalities. VPA –treated men with generalized epilepsy may also have reduced testicular volume.

Healthcare Provider Knowledge re: Epilepsy

- Hormones affect on seizures - 75% unaware
 - Reproductive disorders - 16% aware
 - Interactions between anti-epileptic drugs & oral contraceptive pills - 59% aware
 - Pregnancy risks - 17% aware (4%-6% risk birth defects)
 - Sexual functioning - 11% aware, 64% not sure
 - Risk for osteoporosis - 33% aware, 44% not aware
- Epilepsy Foundation Association, 1998

Access to Healthcare Services

- Structural barriers to receiving adequate and informed reproductive care include
 - limited professional training and competency of primary care and reproductive care specialists;
 - inadequate or no health insurance coverage for visits to specialists;
 - poor physical access to usable and adapted or specialized examination and diagnostic equipment;
 - and negative or discriminatory provider attitudes.

Gender Identity/Expression and Sexual Orientation

- People with disabilities are represented across the sexuality spectrum
 - Gender identity/expression – who you identify as may be different from birth sex
 - Sexual orientation – enduring pattern of romantic or sexual attraction - gay, straight, lesbian, bisexual, transgender
- University of Minnesota study of transexuals who identified as women 38% were bisexual, 35% were attracted to women, and 27% were attracted to men.

Domestic Violence and Sexual Abuse

- Estimates of abuse among women with disabilities ranges from **33%-83%** depending on the definition.
- Only 2-3 % of perpetrators of sexual abuse on persons with intellectual disabilities were unknown to the victim.
- It was estimated that exposure to the disability service system increased the risk of sexual victimization by **78%**
 - Glover-Graf, N & Reed, B (2006)

Compared to non-disabled women, women *with* disabilities:

- Experience abuse for longer duration
 - Were more likely to be abused by a greater number of perpetrators
 - Reported a higher number of health care workers & attendants as perpetrators,
 - Noted few options for escaping or resolving the abuse.
-
- Cramer, E, Gilson, S, & DePoy, E. (2003)

Additionally...

- Abuse against women with disabilities incorporates a greater variety of abusive acts (chemical restraint, withholding meds or mobility aids, humiliation).
- ...there is often a societal failure to notice, protect, believe and prosecute abuse against women with disabilities.



He takes me shopping
then takes my money

He takes me to the doctor
then denies me medication

He helps me to bed
then rapes me

He tells me he loves me
and that no-one else would

Disabled women and domestic violence – it's time to take action

Leaving an abusive relationship is difficult enough – it's even harder if you are a disabled woman – especially if your abuser is also your carer.

There is help and support available:
Go to www.womensaid.org.uk for the Women's Aid Survivor's Handbook, available in 11 languages and audio version, as well as the UK Domestic Abuse Directory.

www.womensaid.org.uk/disability

Published by Women's Aid Federation of England 2008. Registered Charity No. 1004154 UK Registration No. 850 3437 31.

women's aid
uncol women & children are safe
www.womensaid.org.uk

Freephone 24 Hour National Domestic Violence Helpline **0808 2000 247**
Run in partnership between Women's Aid and Refuge

Signs and Symptoms of STDs'

Women

- Pelvic Pain
- Bleeding from vagina between periods
- Burning or itching around the vagina
- Pain deep inside the vagina during intercourse

Women and Men

- Abnormal discharge from penis or vagina
- A burning sensation during urination
- Sores, bumps, or blisters near mouth, rectum, or genitals
- Flulike feelings
- Redness and swelling in the throat
- Swelling in the groin area

Factors associated with positive adjustment

- Level of sexual knowledge,
- Openness and communication w/partner
- Self-esteem

Disability and
Illness: SCI
5/04/2005

Strategies

- Address birth control and testing for STDs
- May have enhanced sensation above the lesion so arousal and satisfaction depend on stimulation there.
- Deal with the catheter.
- Plan a clean out of bowel prior.
- Acquire water-based, over the counter lubricants
- Use assistive technology to stabilize or enhance movement, to cross the threshold of sensation, to creatively and playfully enhance foreplay.
- Learn your body and build your communication skills to convey what feels good and what doesn't.

Getting to know self

- We can increase awareness to areas of our body where sensation is still intact and where we may be open to sexual stimulation
 - Sensate Focus exercises (Drs Masters and Johnson)
 - Pleasure mapping (Dr. Stubbs)
 - Charting your personal extragenital matrix (Drs Whipple and Ogden)

Vocabulary for communication

THE ANATOMY OF PLEASURE

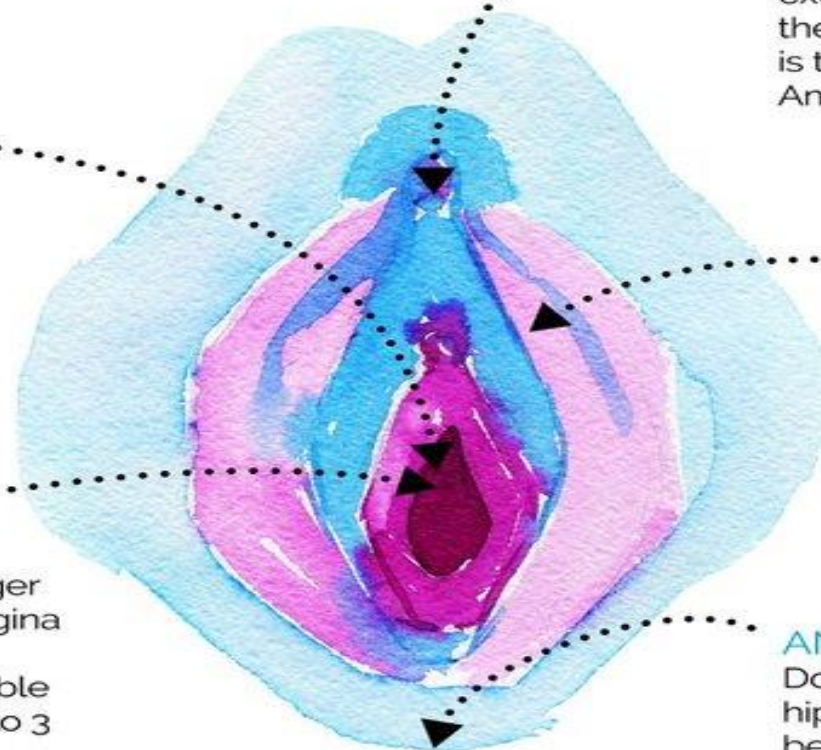
Vulva

VAGINA

Yes! Did you know that nerve endings are mostly in 1/3 from the vaginal opening, so you don't necessarily need super long equipment for maximum pleasure? Guys, stop worrying so much!

G-SPOT

If you were to insert a finger a few inches into your vagina and make a "come here" motion with it, you'd be able to find your G-spot. It's 2 to 3 inches from your vaginal opening on the front wall of your vagina.



CLITORIS

Most of us know this little gal, but it is actually not that little -you can only see a fraction of it! The clitoris is a shape of a wishbone and extends about 3 inches into the vagina. Fun fact: Clitoris is the Greek word for "Key." Amen.

LABIA

The clitoris gets all the attention but there's an outer labia and inner labia that are also full of incredible nerve endings for pleasure.

ANUS

Doin' da Butt- Ow! We heart hip-hop from the 80s! Don't be shy, this can be a really fun spot to tickle and tease.

A world view...

“In general, with rare exceptions, people with disabilities do not get asked if they want to have children. They don’t get asked if they want to be sexual. The silence around sexuality includes their parents, their counselors, their teachers, and most health professionals. Yet these same people sometimes counsel in favor of involuntary sterilization.”

Corbett Joan O’Toole and Tanis Doe, international disability activists
“Rocking the Cradle”, National Council on Disability, 2012

Concerns of Males

- Getting or sustaining an erection
 - Low libido from seizure meds
 - Suppressed testosterone from seizure meds.
 - Fatigue from spasticity meds.
- Ejaculation
 - Premature ejaculation
 - Retrograde ejaculation limits fertility
- Hormones,
 - Could be brain (the body's largest sex organ!) or hormonal
 - See physician regarding drug side-effects or interactions.

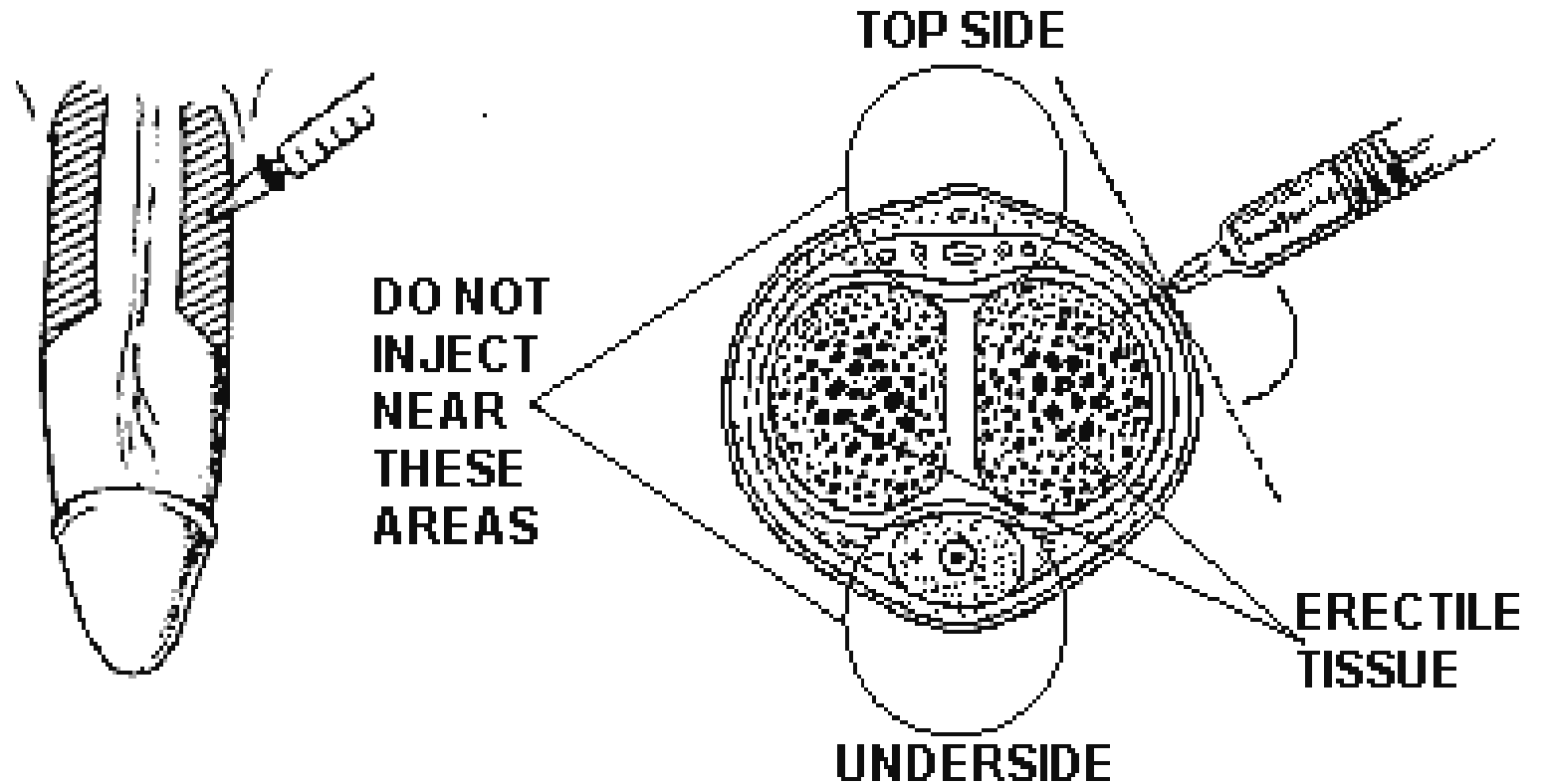
Mechanical Methods

- Vacuum Constriction Devices:
 - partially pd by MA/MC
- Erectaid \$80-\$200
- **VACURECT™ \$229**
 - 30 minutes max for constriction ring!
 - may cause bruising
 - use gel or judicious snipping of pubic hair to improve seal
- Some report it works better if partial erection achieved before VCD
- Usually firm but may swivel at the base/constriction ring



Injections

- Effective in 80-90% of males with ED
- Thin needle; majority of may rate 2 or less on 1-10.
- dosage regulated to produce an erection that lasts more than 20 minutes but less than 2 hours.
- Arterial damage if more than 3 hours
- use 1x in 24 Hr; not more than 3x/wk (scarring)



Implants

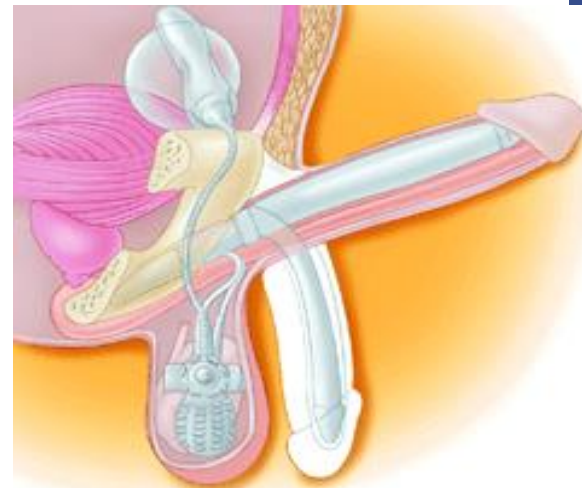
2 firm but bendable silicone cylinders.

- Come in different lengths and widths
- High level of satisfaction with these.
- Least expensive, most painful recovery
- Best option if limited hand function.



2 & 3 piece implants

- 2 piece has a pump that is both the fluid reservoir and the pump.
- Has a release ring for quick inflation and deflation.
- Features an integrated injection port for easy intra-operative filling and post-operative fluid adjustment.
- Generally requires a day or two hospital stay
- 3 piece produces a natural looking erection (fuller and firmer) and feels softer and more flaccid when deflated than 1- or 2-piece implants



Effectiveness of erectile dysfunction interventions

- Moemen *et al.* compared the effectiveness and satisfaction associated with use of several ED therapies including sildenafil alone, intracavernosal injections (ICI) followed by sildenafil after ICI discontinuation and vacuum erections devices (VED) followed by sildenafil therapy after VED discontinuation. **Seventy percent** of men receiving vasoactive medications **preferred sildenafil** to ICI, even though **rigidity was superior in the ICI** group. All men using VEDs were dissatisfied with that form of therapy.
- The **duration of erections is also improved by sildenafil** from 8.4 to 10 minutes when compared to baseline. (Gans *et al.*) Men using sildenafil were also more confident that they could maintain their erection compared to prior therapies such as VEDs (**65**).
- The presence of an upper motor neuron lesion up to T12 suggests a successful response
- The ease of use and tolerability of sildenafil has also led to improved satisfaction and quality of life

Treatment for Women

- **Enhancing stimulation.** This may include the use of erotic materials (videos or books), masturbation, and changes in sexual routines.
- **Encouraging non-coital behaviors.** Non-coital behaviors (physically stimulating activity that does not include intercourse), such as sensual massage, can be used to promote comfort and increase communication between partners.
- **Minimizing pain.** Using sexual positions that allow the woman to control the depth of penetration may help relieve some pain. Vaginal lubricants can help reduce pain caused by friction, and a warm bath before intercourse can help increase relaxation and a sense of confidence in personal hygiene.

Further complicated in menopause

- Atrophy of the vaginal structures
- extreme dryness
- hot flashes
- osteoporosis
- mood swings
- cancer

Note: For people prone to urinary tract infections, make sure to pick up a lubricant to reduce friction and irritation during sex.

Silicone- vs. water- vs. oil-based lubricants

- **Silicone** lube is incredibly slippery, and lasts significantly longer than water-based lube making it ideal for sex acts like hand jobs, vulva massage, and anal play. This lube is a great option for shower play. It must be washed off with soap.
- **Water**-based lube is smooth and slick, but not sticky and messy like silicone and oil-based lubes can be. Look for fragrance-free. Water-based is both toy- and condom-safe. Note: many water-based lubes contain glycerin, which can promote infections in women and make quick post-sex clean-up mandatory.
- **Oil**-based lubes aren't as popular as the previous two kinds. First, they tend to corrode latex, so you can't use them with condoms. Second, they're usually made with ingredients that are bad for women's vaginal health. And finally, they're slimy and messy.

Vaginal dilators

“

“Loved the dilators because they have a handle and are easier for patients to use.”
— Hollis Herman, MS PT
OCS BCIAC-fellow

“

“Thank you... your dilators were a tremendous help.”
— L.J.

“I would recommend these dilators to anyone”
—Barbara Smith, MA, Psychotherapist—



Treatment for couples



Education and information

- Moisturizing and lubricating products to alleviate dryness and pain
 - Assistive Technologies
 - Gradual dilation of the vaginal opening
 - Systematic desensitization to vaginal insertion
 - To discuss concerns frankly regarding sexual and reproductive health with a doctor, they may benefit from role play to practice speaking aloud their thoughts.
-
- Communication and exploration – figure out what works best **together**.

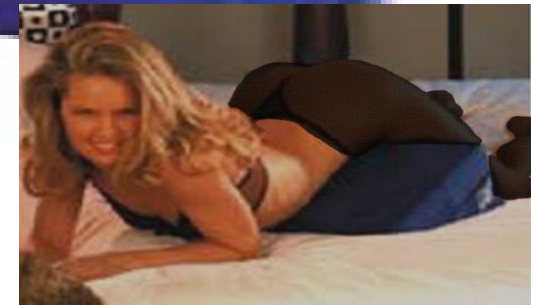
Positions

- One that is physically comfortable and allows you to do what you want to do.

<http://sexuality.about.com/od/sexualpositions/ig/Sex-Positions-Image-Gallery/>

- Support
- Movements
- Angle
- Speed & Pacing

Liberator Wedge



Versa Form



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The challenge is no longer
How can we be intimate?
but **How Intimate
Can We Be?**

Start Learning More

A promotional banner for IntimateRider. On the left, a man and a woman are shown in a close embrace, about to kiss. On the right, a black metal frame product, consisting of a long low table and a chair, is displayed on a wooden floor. The text is overlaid on the right side of the image.

Good info on positions with links <http://www.intimaterider.com/>



Vibrators

- Hands free models available
- Extended handles
- Note: Vibrators heat up with use (15 minutes or less) so watch for reddened skin if decreased sensation.





Tips & Resources

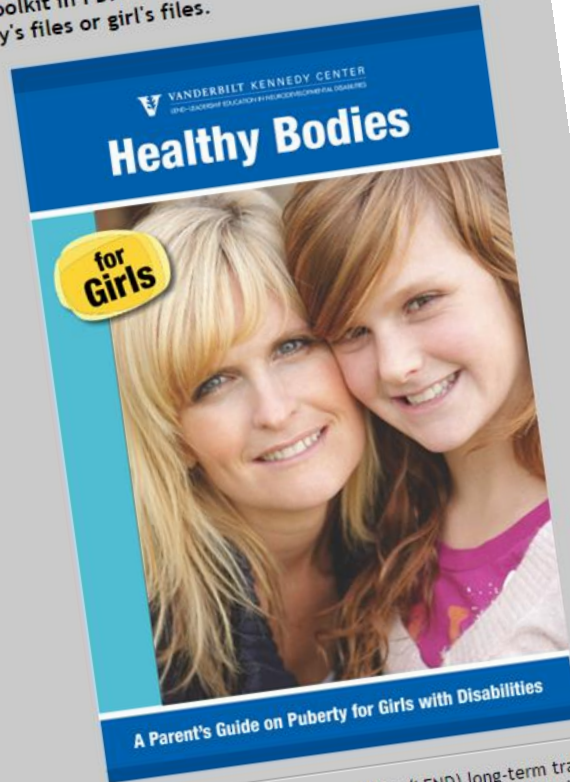
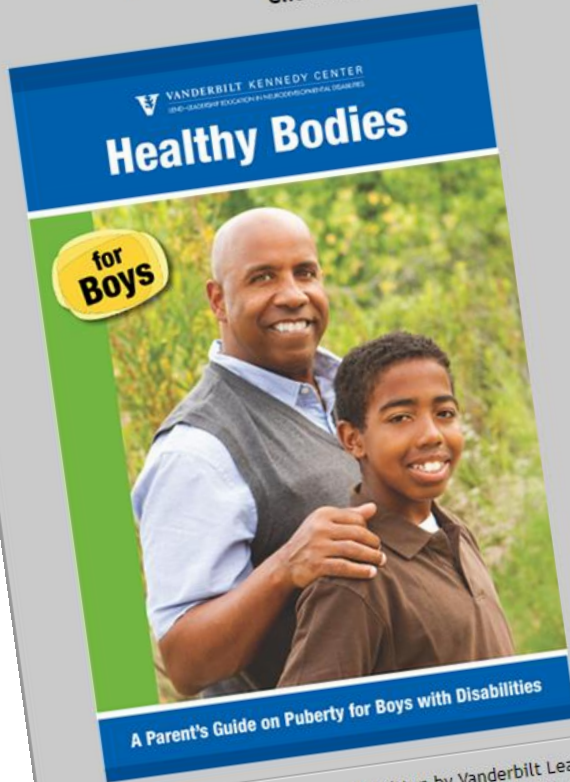
Tips for Professionals and Parents

- Read it/view it first. Is it in line with your norms, is it age appropriate, and is it safe?
- Watch your timing. Allow time to process info, answer questions, allay anxiety.
- Don't oversell it.
- Follow their lead. Find out what their concerns are & what they are comfortable discussing.
- Let it sink in. Come back to it to assess understanding. "Tell me what you think about..."

The Healthy Bodies Toolkit

en español

This site contains files for the Health Bodies Toolkit in PDF format for your use.
Click the picture to select the boy's files or girl's files.



This publication was developed and written by Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) long-term trainees Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; Doctor of Audiology student, Elizabeth Harland; Cong Van Tran, PhD; and LEND faculty members Jennifer Bowers, RN, MSN, CPNP, Pediatric Nurse Practitioner, Division of Developmental Medicine; and Cassandra Newsom, PsyD, Assistant Professor of Pediatrics, Division of Developmental Medicine. It was edited, designed, and produced by the Communications and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) with the support of the Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). We are grateful for review and suggestions by many, including faculty of TRIAD and members of Autism Tennessee.

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thybodies//boys.html

For Children & Young teens:

Story boards/Pictures for teaching:

- Public/Private
- Touch
- Tanner stages
- Hygiene

FREE & downloadable

<https://vkc.mc.vanderbilt.edu/healthybodies//>

Talk Sex with Sue.com

- **Sue Johanson** [Retired] is Canada's foremost sexual educator and counselor, recipient of the distinguished Order of Canada.
- Web Q & A
- Author



Queer
Questions
for Dr Keith

“Sex is Perfectly Natural, But Not Naturally Perfect”

-Sue Johanson

RAISE Center Begins Blog Series on #MeToo and Disability

April 30, 2018 [Leaders](#) | [Resources](#)

The National Resources for Advocacy, Independence, Self-determination and Employment (RAISE) Technical Assistance Center published the [first in a series of blogs](#) that address the intersection of disability and sexual assault and abuse. The four-part series features personal stories from guest contributors who have bravely shared their experiences as people with disabilities coping with the aftermath of the sexual assaults they endured and its relevancy to the disability.

<https://raisecenter.blog/2018/04/13/disability-and-metoo-part-1/>

<https://veracvs.adobeconnect.com/pdiog6avzu6r/?proto=true>

Sexuality and Consent PPT Final.pptx

It's My Prerogative: Consent and Healthy Sexuality for People with Disabilities

Katherine McLaughlin

August 21, 2018

ELEVATUS TRAINING

LEADERS IN SEXUALITY AND DEVELOPMENTAL DISABILITY

Dr. Danielle Sheypuk gets real about sex and disability

Tedx

Barnard
College



It is important to provide people with Spina Bifida with opportunities to acquire relevant and accurate knowledge about sexual health, and to develop and implement skills to negotiate sexual desire, intimacy, and activity. Doing so can support healthy sexuality while limiting negative outcomes of sexual activity related to sexually transmitted infections, HIV transmission, unintended pregnancy, or sexual exploitation. - *Guidelines*

