

**Holland Bloorview**  
Kids Rehabilitation Hospital



## Teens and young adults with neuromuscular conditions, these handouts were designed for you!

If you're reading this, it's probably because you're looking for more information about dating, relationships, sex, or all of the above. In case you were wondering, people who have neuromuscular conditions can and do have meaningful emotional and physical relationships. We have included information in these handouts about topics ranging from friendships and relationships, to consent, to positions for sexual exploration. You can look at as much or as little as you're comfortable with. We're glad you're interested in exploring, and while this is a good place to start, these handouts are meant to be part of a bigger conversation with a trusted person in your life like a parent or a healthcare professional (a doctor, occupational therapist, physiotherapist, social worker, or speech language pathologist, to name a few).

If you have questions about what you read, or if you're interested in exploring a topic further, we encourage you to bring these handouts to your healthcare team. You may even want support problem solving or planning around a personal situation. We know it can feel intimidating or uncomfortable to start conversations about dating, relationships, and sex, but they are important! Sexual health is part of your overall health and you have a right to learn about it and explore within your comfort level.

Happy reading,

Amanda and Charise

On behalf of the Guidebook Team

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# Friendships, relationships, and dating



## Friendships

Everyone needs friends. Making friendships outside of school can be challenging and takes effort. Many teens experience loneliness, which can be an isolating experience. While there is not one easy solution, this resource includes tips and ideas to build and keep friendships and relationships.

### Some ways to meet friends are:

- Get involved in activities you enjoy to meet people and stay in touch.
- Build on interests developed in school and look for similar community activities or clubs (e.g. film, art, photography, sports, gaming, robotics, nature, etc.).
- Reach out to peers with similar interests before graduating from high school.
- Once you know someone, share your contact information or connect on social media.

**Having fun is important!**  
**Fun helps you stay connected to others, and feel good about yourself.**

### What can I do if I need help with building or keeping friendships and relationships?

- Ask for help. Talking to your family doctor, guidance counsellor, social worker, or a person you feel safe with can be a helpful first step.
- Coaching or counselling programs might be helpful for you. Ask your local service providers if these are available to you.
- If you are having difficulty participating in activities you enjoy or want to try, work with family members, friends, an occupational therapist, or recreational therapist to adapt activities. Most activities can be changed in some way so you can join in (e.g. adaptive sports, art programs, music, photography, fishing, to name a few).
- Joking around is part of friendships, but teasing and unkind comments or actions are bullying. If you are experiencing bullying, tell an adult you trust such as a parent, teacher, social worker, guidance counsellor, etc.

## Romantic relationships, dating, and sexual health

Dating and sexual health are important parts of life and your general health. People with neuromuscular conditions can and do date and have relationships. The foundation of dating is forming meaningful connection with another person. Your disability shouldn't be the main focus of your relationship. However, it will be important to discuss what you need and like with your partner, which may include how your disability affects your sexual expression.

## Some tips for forming romantic relationships and dating:

- Get to know different people so you can learn who and what is attractive to you.
- When you meet someone, either online or in person, who you are interested in getting to know more, you may decide to go on a date.
- For dates in person, planning can take some time and thought. Think about the accessibility of the location of your date, including bathrooms. This can make going out more complicated. Your date, parents, or therapist can help you with this planning.



**There are many city-specific apps that provide accessibility information about stores, restaurants, and other destinations.**

## What can I do to explore my sexual health?

- Ask your caregivers for privacy so you can get to know your body.
- You might want to explore your body and sexual expression on your own. This is normal and there are lots of ways to do this.
  - Based on your own needs, you may want to consider energy conservation, positioning, and toys & tools.
- It is important to consider your risk for Sexually Transmitted and Blood Borne Infections (STBBIs) and pregnancy when you are engaging in partnered sexual activities. Talk to your doctor if you have questions about your medications or other factors that may impact your risk.
- Ask your personal support worker (PSW)/attendant to help with set-up of activities or clean-up, if needed. You should have privacy during sexual activities.

**If your family uses a video/audio monitor to support care, arrange for them to be off during predictable times for your privacy.**

## Where can I get information about relationships and sex?

- If you have any questions about sex or your body, talk to your physician or your therapy team. Start with whomever you feel most comfortable talking to.
- Let's Talk About Disability and Sex online hub has information you might find helpful, [HollandBloorview.ca/sexuality](https://HollandBloorview.ca/sexuality)
- Muscular Dystrophy Canada offers some sessions on dating, relationships, sexual expression and woman's health that can be found on YouTube, *If I Knew Then What I know Now: A Transition to Adulthood*, 2021.
- Local resources and stores may sell devices that can help you explore your body or engage with a partner. They may also offer workshops.
- There are additional handouts about a variety of topics related to sexual expression included in this resource that you may find helpful.

**Talking about sex might feel awkward, but you have a right to talk about it, and it gets easier with time.**

## References and resources

1. Muscular Dystrophy Canada, YouTube, "If I knew then what I know now" – Sexuality, intimacy and relationships
2. Muscular Dystrophy Canada, YouTube, "If I knew then what I know now" – Women's health
3. Love, Dating, Relationships, Disability. Easter Seals. <https://www.easterseals.com/explore-resources/living-with-disability/love-dating-relationships-disability.html#dating>
4. Holland Bloorview Kids Rehabilitation Hospital (2022). Let's Talk Disability and Sex online hub. Available at: [HollandBloorview.ca/sexuality](https://HollandBloorview.ca/sexuality)

## Consent and relationships



### What is consent?

Consent means agreeing to participate in, or do a task. Consent in romantic relationships applies to all physical touch and sexual activities, including online activities like sexting and sharing pictures. You have the right to say “no” to anything your friends or sexual partner ask you to do, and you don’t need a reason. This can also include participating in activities with friends that you don’t want to do, or consuming drugs or alcohol. Consent and communication are very important in any relationship.

### When do I need to get or give consent for sexual activities? Consent is essential and ongoing.

- Every time you participate in sexual activity (in person or online), you need to get and give permission.
  - E.g. If you provided consent once, it does not mean that you have given permission for that activity forever.
- You and your partner have the right to say “no” to physical touch or sexual activity anytime, even during the activity.
- A person cannot give consent if they are drunk or high.
- If someone continues with a sexual activity after being told with words or gestures that the other person wants to stop, they are committing a criminal offence.
- If someone shares a photo with you, or you share a photo with someone else, it should not be sent to anyone else or posted online without permission. It is illegal to share nude images of people under 18 years of age.



### What does it look like to give/get consent?

More examples of how to give and get consent can be found in the Planned Parenthood resource: [How Do You Know If Someone Wants to Have Sex With You?](#)

- Consent can be **given** with:
  - Words (spoken or written): e.g. “Yes, I would like for you to kiss me”
  - Body language: e.g. nodding and smiling
  - Use of alternative communication including augmentative communication and texting.
- You can **get** consent with:
  - Words (spoken or written): “Would it be okay if I kissed you right now?”



Your condition might make it difficult to smile or show dislike through facial expressions. It may also impact how easy it is for others to understand you when you talk. If this is the case for you, come up with a plan for communication in advance so that you can give, continue or end consent. Clear communication is also important so you and your partner can let each other know what you need and like. Your communication plan could include speaking verbally or using written communication.



**Check out this graphic story “Building Consent Castles” by Everyday Feminism for further information on consent conversations: <https://everydayfeminism.com/2016/07/metaphor-for-consent/>**

### Attendant care and caregiving

- Consent is an important part of receiving care.
- Caregivers should not touch you without permission and should receive your consent when providing care to you.
- Part of your role is to direct your care, or tell your caregiver how you want them to do things for you. It can be hard to tell caregivers how to care for you. You can practice with familiar people or simpler tasks to start.
- If you don't like how a caregiver is touching or moving your body during care, it is important to tell them, or to tell another adult who can help you communicate your needs.
- Caregivers can support you with sexual expression by helping you with positioning, managing clothing, set-up, and clean up, as directed by you. Your caregiver should give you privacy during sexual activities.
- If a caregiver is touching you in a sexual manner, it is important to tell a safe adult who you trust.



### References

1. Government of Canada - <https://www.justice.gc.ca/eng/rp-pr/other-autre/clp/faq.html>
2. Everyday Feminism – Building Consent Castles <https://everydayfeminism.com/2016/07/metaphor-for-consent/>
3. Planned Parenthood – How Do You Know If Someone Wants to Have Sex With You? <https://everydayfeminism.com/2016/07/metaphor-for-consent/>

# Energy conservation and sexual expression

## What is energy conservation?

With your neuromuscular condition it might take more energy to move your body and you may need to take breaks. Learning how to make decisions around how you use your energy is important to allow for participation in activities that you have to do, or that you want to do, including sexual activities.

## The 4 P's of energy conservation

### Prioritize

What is most important?



### Plan

Create a schedule/decide what you need in advance



### Position

Set your body up for success



### Pace

Take breaks or slow down



## Prioritize

Consider what activities are **most important** for you to complete in a day. If sexual activity (either with a partner or self-stimulation) is important, make it a priority.

- Within sexual expression, prioritize activities that are most valued or pleasurable for you and/or your partner (if applicable).
- Ask people to help you with other tasks that are lower priority or that are more tiring, or leave them for another day when possible.



With practice, you will learn which activities require more or less energy for you, and which are most important to you and your partner (if applicable). This may range from touch or cuddling, to use of tools, to intercourse (or anywhere in between!)

## Plan

Consider your schedule; plan to engage in activities of sexual expression at times that work for your routine (ex. perhaps when you're already in your preferred position to minimize the need for transfers), at times of day that you have more energy, or times when you will be able to rest afterwards.

- What times of the day do you have more energy?
- Are there times of day that allow for a break after the activity?
- Have any toys or tools clean and ready for use (ex. vibrators, etc.).
- Have a plan for cleaning toys and tools, your body, etc. after the activity.
- Consider availability of a Personal Support Worker or your partner to help you get ready for these activities, or to help you to get up after (transfers, managing clothing, etc.).





## Position

Some positions require your body to work harder than others. An important part of energy conservation is selecting positions where your body is well supported. Positioning is also important for comfort and access to parts of the body.

- Your preferred position for sexual activity may be in your wheelchair, in bed, or on another surface.
- Pillows and wedges can be used to help hold your body in a position that allows you to access your own body or your partner's body. This may take some time to perfect, so communication about what works and feels good to you is essential.



**Ask your therapist for a copy of the *Supportive positioning for sexual expression* handout for more information about these options.**



**Positioning + contractures:**  
Positioning can increase access to parts of your body for you or your partner if you have limited movement in your joint(s).

## Pace

Pacing, either taking breaks or slowing down, is an important strategy to prevent your body from getting too tired. During sexual activities, it may be important to take breaks. Use the skills you already have to listen to your body and follow its cues.

- Use of commercially available tools including vibrators may be helpful to support pacing. These devices can be used by yourself or with a partner (with many different options for control, including through a cell phone).



**Ask your therapist for a copy of the *Toys and tools for sexual expression* handout for more information about these options.**



The 4 P's all work together to help you to save your energy for the activities that are most meaningful for you!



**If you have questions about how to apply these strategies to your daily life, talk to your occupational therapist.**

## Supportive positioning for sexual expression

Supportive positioning for your body is important for safety and comfort when engaging in sexual activity. The following tips can be used with a partner or during self-exploration, which can include, but is not limited to, touching yourself or using toys or tools.

### General tips and considerations:

- How your body is positioned is important for your success with self-exploration, as well as sexual activity with a partner. Your comfort is essential for you to enjoy the experience.
- Use pillows, wedges, and rolled blankets to help with positioning your body for comfort, and to allow you to reach your body or your partner's body.
- It may take time to find the right position(s) for you and for your partner. Take time to try different options to discover what works for you.
- Setting up for sexual activity might include using positioning pillows as well as toys or other tools. This can be done ahead of time, or in the moment.
- Communication with your partner may be impacted by your position. If you use non-verbal, written, or other forms of communication, or if your speech is quiet, you may want to consider a communication plan ahead of time. Communication is essential for you and your partner to know what you enjoy or dislike.
- For more information and assistance with problem-solving around positioning or communication during sexual activity, contact your occupational therapist, physiotherapist and/or speech language pathologist



You can find information about common and specialty positioning pillows in the *Positioning products handout*.

### Positions for sexual expression



**Supine (lying on your back)**

- Place pillows under your lower back and/or knees for support and comfort.
- Pillows can also be placed on either side of your head to help with head position.
- Pillows placed under your knees can make reaching genitals easier for self-exploration.
- Pillows under your pelvis may help to adjust your pelvic angle, which can impact access to your body and your comfort.
- If you have an adjustable bed, try different positions by raising and lowering the head and foot of the bed.
- If you have difficulty breathing when lying flat using pillows, wedges, or raising the head of your bed can be helpful

**Pillow placement, such as under your knees, can help you reach your body for self-exploration.**



Side-lying

- Side-lying may be comfortable if you have less flexibility at your hips or knees.
- While lying on your side, pillows can be placed between your knees and behind your back for support and comfort.
- Pillows between your knees may make it easier to reach your genitals, particularly for self-exploration.
- If lying directly on your shoulder causes pain, you can try semi-side-lying positions. Talk to your therapist about how to do this.



Seated

If you use a power or manual wheelchair:

- If it works for you and/or your partner, you can enjoy sexual activities in your wheelchair.
- Features including tilt and recline can be used to support your body as well as increase positioning options and access to your and your partner's body.
- A seated position can be beneficial for self-exploration as it might be easier for you to reach your genitals.
- If using a manual wheelchair for partnered sexual activity, position the chair with the back against a wall or solid surface for safety. Wheelchairs and equipment like commodes have weight limits. Ensure this is checked before partnered use.
- If your wheelchair has removable armrests and lateral supports, these can be removed to make room for your partner.

**Using your wheelchair for sexual activity can eliminate the need to transfer, reducing overall fatigue.**



Using furniture

- Couches and chairs can also be used for sexual activity.
- Furniture can provide many options for positions that might work for you and your partner.
- You may want to use your commode or other bathing equipment for sexual activities. Sexual activity during bathing might make clean-up easier and fit into your existing routine. Some toys and tools are waterproof and can be used in the shower.

**You can ask for a period of privacy from your caregivers during bathing.**

## Positioning products

There are a variety of products available to support with positioning your body. They range from common items, to more specialized options. Specialized products tend to be more expensive; specific details about products, including costs, can be found on the websites included below or through the resource handout.

Some positioning products that can support sexual expression are described below. There are lots of options available. The examples in this handout highlight features that can help you make decisions about what will best meet your needs. Occupational therapists and physical therapists are experts in positioning and can help you with this.

**Caregivers, attendants, or your partner can set up positioning products and help with transfers/positioning.**

### Hospital bed

These provide the option to change the angle of the head and foot of the bed, as well as height of your bed (e.g. to accommodate a partner standing at your bedside or in a mobility device).

### Pillows and rolls

Standard pillows and rolls can be used to provide support and comfort in a variety of positions. Work with your caregivers, partner, occupational therapist, or physical therapist to find positions that are most comfortable for you. For sexual activity or exploration, placing a roll or pillow can change access to the parts of your body you, or your partner are interested in exploring.

If pillows are not providing enough support, there are positioning products that may be helpful.

### General wedges and rolls

Look up local equipment vendors or distributors to explore rolls and wedges to support your positioning. Ask your therapist and see the [Resources and additional reading](#) handout for more information about where to purchase equipment.

Image reference: <https://www.prohealthcareproducts.com/skillbuilders-therapist-kit-1-wedge-roll-half-roll/>



### Liberator shapes

Foam positioning pillows are available in a variety of shapes

Image reference: <https://www.amazon.ca/Liberator-Wedge-Ramp-Combo-Short/dp/B001A3FIVM>



### Love bumper iceberg

These foam positioning pillows contain openings to insert devices such as vibrators. These pillows are available in a variety of shapes.

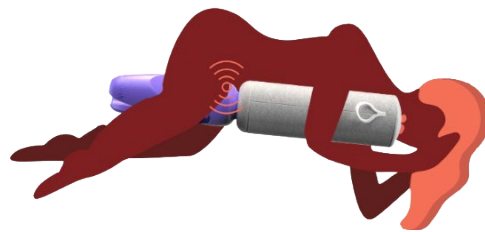
Image reference: [http://www.goodvibes.com/display\\_product.jhtml?id=17BF18&kbid=42691](http://www.goodvibes.com/display_product.jhtml?id=17BF18&kbid=42691)



### Bump'n joystick

This is a large flexible foam cylinder that can bend and shape to your body and can hold sex toys (vibrators, dildos, sleeves). It can be held in a variety of positions.

Image reference: [www.getbumpn.com](http://www.getbumpn.com)




## Toys and tools for sexual expression

Toys and tools can be used by individuals for self-exploration and/or with a partner. Self-exploration can include, but is not limited to, touching yourself or using devices on your own. Due to your condition, you may experience muscle weakness and loss of sensation, making it difficult to hold or use some toys.. Toys with different accessible features can be used to suit your physical abilities and support play. If you are having trouble using devices or having difficulty with positioning when using devices, talk to your occupational therapist or physiotherapist for further recommendations, and possible adjustments to toys.



See **Supportive positioning for sexual expression handout and/or your therapist for more information.**




We have included considerations for toy selection below with some examples. The goal of this chart is to help you understand options and considerations when selecting a toy. There are many, many other options within each category that you can explore to find something that will best meet your needs!

Toy type	Good to know	Example	Easy to grasp	Hands free	External stimulation	Internal Stimulation	Individual use	Partnered use	Wearable	Bluetooth Option available	Oral sex
Used in underwear or pants	Caregivers can set up device for an individual to use privately	Moxie;Eva II Can be worn in underwear or clipped on other clothing.   Image reference: <a href="https://www.we-vibe.com/ca-en/moxie-plus?gclid=Cj0KCQjwldKmBhCCARIsAP-0rfyvYSd-XgKhpLReWywO6P0_9HT-s-I5bEzeJ062V8xpoCHkXPPoPE8aAjdEALw_wcB">https://www.we-vibe.com/ca-en/moxie-plus?gclid=Cj0KCQjwldKmBhCCARIsAP-0rfyvYSd-XgKhpLReWywO6P0_9HT-s-I5bEzeJ062V8xpoCHkXPPoPE8aAjdEALw_wcB</a>	●	●	●		●	●	●	●	

Teens, Sex and Neuromuscular Conditions: A Practical Guide



Toy type	Good to know	Example	Easy to grasp	Hands free	External stimulation	Internal Stimulation	Individual use	Partnered use	Wearable	Bluetooth Option available	Oral sex
Manual masturbation sleeve	Fleshlight travel models are lighter in weight. Efficacy may vary depending on penis size. PVC inflatable option will be lighter weight and allows adjustability for penis size.	Go Fleshlights  Image reference: <a href="https://fleshlight.zendesk.com/hc/en-us/articles/360014581053-Fleshlight-Flight">https://fleshlight.zendesk.com/hc/en-us/articles/360014581053-Fleshlight-Flight</a>	●		●		●	●			
Vibrating masturbation sleeve	Does not require an erection to use. The Satisfyer and Blowmotion provide a tighter fit.	Blowmotion suction vibrating male masturbator  Image reference: <a href="https://www.amazon.co.uk/Lovehoney-Masturbator-Black-Blowmotion-Rechargeable/dp/B08P7VJQZJ">https://www.amazon.co.uk/Lovehoney-Masturbator-Black-Blowmotion-Rechargeable/dp/B08P7VJQZJ</a>	●		●		●	●	●		
Worn on finger		Fin vibrator – finger vibrator  Image reference: <a href="https://mysecretluxury.com/luxury-vibrators/clitoral-and-external-vibrators/fin-by-dame-finger-vibrator">https://mysecretluxury.com/luxury-vibrators/clitoral-and-external-vibrators/fin-by-dame-finger-vibrator</a>	●		●		●	●	●		


Teens, Sex and Neuromuscular Conditions: A Practical Guide

Toy type	Good to know	Example	Easy to grasp	Hands free	External stimulation	Internal Stimulation	Individual use	Partnered use	Wearable	Bluetooth Option available	Oral sex
Flexible	Can be bent to help with access and/or holding.	<p>Lelo Picobong Transformer</p>  <p>Image reference: <a href="https://www.delicto.com/en-ca/products/picobong-transformer-vibrator">https://www.delicto.com/en-ca/products/picobong-transformer-vibrator</a></p>	●		●	●	●	●			
Pressure control	Squeeze to operate – *degree of pressure required varies by device.	<p>Egg Massager Passion Set</p>  <p>Image reference: <a href="https://www.dallasnovelty.com/shop/disabled-sex-toys/sola-egg-passion-intelligent-4-in-1-pressure-sensitive-rechargeable-massager-set/">https://www.dallasnovelty.com/shop/disabled-sex-toys/sola-egg-passion-intelligent-4-in-1-pressure-sensitive-rechargeable-massager-set/</a></p>	●*		●		●	●			
Vibrator	Can be used through buttons or a Smartphone app 1 talk to your therapist about how to make it easier to hold 2 once in place some vibrators can be controlled using a smart phone or remote	<p>We-Vibe Rave</p>  <p>Image reference: <a href="https://joyviva.ca/products/we-vibe-rave">https://joyviva.ca/products/we-vibe-rave</a></p>	● <sup>1</sup>	● <sup>2</sup>	●	●	●	●		●	



Teens, Sex and Neuromuscular Conditions: A Practical Guide

Toy type	Good to know	Example	Easy to grasp	Hands free	External stimulation	Internal Stimulation	Individual use	Partnered use	Wearable	Bluetooth Option available	Oral sex
Wand	Consider size and ease of pushing buttons 1 talk to your therapist about how to make it easier to hold 2 problem solve or ask a therapist about positioning to support hands-free use	Doxy Wand  Image reference: <a href="http://www.amazon.co.uk/Doxy-Massager-Plug-Vibrating-Black/dp/B00N8TC3CS">http://www.amazon.co.uk/Doxy-Massager-Plug-Vibrating-Black/dp/B00N8TC3CS</a>	● <sup>1</sup>	● <sup>2</sup>	●		●	●			
Tongue	There is an optional ear piece to help secure in place.	Tongue Star Pleasure Tongue Vibrator  Image reference <a href="https://www.amazon.com/Tongue-Pleasure-Star-Vibe-Oral/dp/B086GYRHZB">https://www.amazon.com/Tongue-Pleasure-Star-Vibe-Oral/dp/B086GYRHZB</a>		●	●			●	●		●

Toy type	Good to know	Example	Easy to grasp	Hands free	External stimulation	Internal Stimulation	Individual use	Partnered use	Wearable	Bluetooth Option available	Oral sex
Pelvic, thigh or hand harness		Aslan Leather Double Up Dildo Cuff; Unicorn Collaborators Thigh Harness  Image reference: <a href="https://www.comeasyouare.com/products/unicorn-collaborators-thigh-harness">https://www.comeasyouare.com/products/unicorn-collaborators-thigh-harness</a>		●	●	●		●	●		

### Good to know ...

**Lubricants:** Lubricants can improve your and your partners’ experience and pleasure with and without toys. Lubricants or “lube” comes in bottles or, less commonly, in single-use packets. If you have difficulty opening packets or bottles, you might want to try bottles with a pump, adapted bottle holders, and/or automated dispensers as they may be easier to use.

**Hygiene and care of toys:** It is important to use clean toys to prevent infections. Caregivers can support you with sexual expression by helping you with set-up and clean up, as directed by you. Clean up does not need to occur immediately after use but should be completed at some point after each use.

**There are different types of lubricant – do your research to confirm which is best for you and the toys/contraceptives you are using.**

### Resources

1. <https://www.crippingupsexwitheva.com/>
2. <https://www.amazon.ca/Queers-Wheels-Eva-Sweeney/dp/1451521243#customerReviews>

## Sexual expression and staying safe



### Sexual expression – What is it, anyway?

- Sexual expression includes:
  - self-exploration (e.g. looking at images, touching your body, masturbation).
  - partnered sexual activities (e.g. kissing, touching your partner’s body).
- There are many activities you can do to express your sexuality on your own and/or with a partner.
- Everyone has the right to safe, consensual, and fun sexual expression.

Looking for more information on sex? While it is okay to talk with your friends about sex, they may not have the best information. Talk to your parents, a health care provider, and/or check out our [Resources and additional reading](#) handout for information.

### Getting to know yourself

Getting to know yourself is an important building block for sexual expression. If you don’t know what you like, it’s difficult to explore it further, or let your partner know. Some ways to get to know yourself as you begin to explore your interest in sexual expression are:

- build awareness of your values and boundaries;
- explore who and what activities you are attracted to and interested in;
- spend time getting to know what feels good for your body;
- thinking/fantasizing, erotic books, exploring pornography, touching your body, talking to others.

**Sexual expression starts with learning about and exploring your own body and emotions.**



**If you want more ideas about how to explore your body, ask your therapist for the *Supportive positioning for sexual expression and Toys and tools for sexual expression* handouts.**

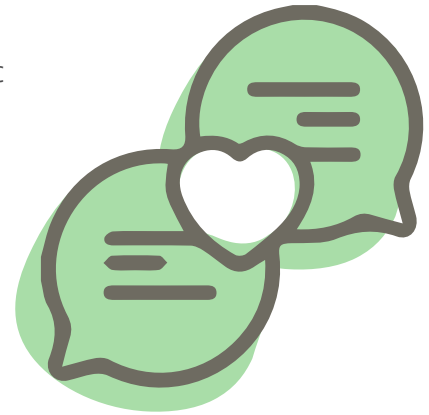
### Gender and sexual orientation

A part of self-exploration is getting to know your identity and sexual/romantic attraction. This looks different for everyone and may change over time. There are lots of great resources in this area. Check out the [Resources and additional reading](#) handout for more information.

## Myths about sex

There are lots of myths about sex, so let's clear some things up!

- Sex does NOT only mean intercourse (i.e. vaginal or anal penetration).
- Having an orgasm is NOT the goal of sexual activity – you can have lots of fun without having an orgasm.
- Sex does not always feel amazing and comfortable and not everyone likes all types of touch – it can be awkward when you are figuring things out! Sex should not be painful. Knowing your body, and good communication with your partner are key.
- Sex is NOT a way to prove that you love someone. Love can exist without sex and everyone is worthy of love!
- Your body does not need to look a certain way. Pornographic materials often show exaggerated bodies and anatomy.
- Not everyone likes the same things. Different people like different things. What you like may change over time.



## Safe sexual expression

“Safe” sexual expression refers to reducing the risk of pregnancy and/or sexually transmitted and blood borne infections (STBBIs).

## What do you need to know to stay safe while having a good time?

- You can choose activities that are lower risk (e.g. cuddling, or rubbing your partner's genitals over their clothing has no risk of pregnancy and/or STBBIs).
- You can use contraceptives. Contraceptives are tools that prevent pregnancy. Examples include: intrauterine devices (IUD), condoms and the birth control pill. Not all contraceptives prevent STBBIs.
- Only condoms prevent STBBIs and pregnancy.
- If you are engaging in sexual activities, it is important to share this with your doctor so that they can provide you with important health information, screening, and the best contraception options for you.
- Learn more about STBBI's on the Kids Help Phone website:  
<https://kidshelpphone.ca/get-info/preventing-stis-info-about-protection-safer-sex/>
- Learn more about methods of contraception on the Kids Help Phone website:  
<https://kidshelpphone.ca/get-info/preventing-pregnancy-info-about-birth-control-safer-sex/>

## Questions to ask your doctor

Based on what you have heard or read, you may have more questions about sexual health. You are encouraged to talk to your doctor about any questions you have. We have included some common questions, but you may have more. It is important to ask any questions you have, they are all valuable.



### My body

- What is puberty?
- What does puberty mean for my body? How will my body change?
- What are my options for managing my period (e.g. period suppression, period underwear, hygiene, etc.)?
- What can I do if I'm not experiencing puberty like other teens?
- I have questions about my gender identity, who can I talk to about this?

### Sexual health

- When should I start having physical exams and screenings related to sexual health?
  - What is a physical exam?
- I am sexually active what screening and testing for sexually transmitted and blood borne infections (STBBIs) are recommended?
- What are my options for birth control and protection from STBBIs?
- General questions about sexuality or sexual health, for example:
  - Will I be able to have children?
  - Who can I talk to about genetic counselling and if my kids will have my condition?

**It's never too early to ask about sexual health, and there are no silly questions. Your doctor has lots of great knowledge for you to benefit from.**

### Sexual performance

- Does any of the medication I take change my sexual performance?
- Does my condition have an impact on my sexual performance?
- Does my condition change sensation in my genitals?
- Contact your doctor if you experience pain or discomfort during sexual exploration.
- Is there any information about use of vibration in my condition?
  - Many toys and tools for sexual expression have vibrating features.

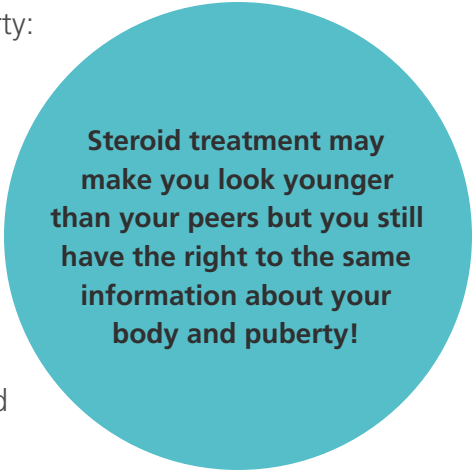
# Duchenne Muscular Dystrophy, steroid treatment, and puberty

## Steroid treatment

Many people who have Duchenne Muscular Dystrophy (DMD) receive steroid treatment (ex. Deflazacort, Prednisone, etc.) to protect the muscles in their body. This medicine has many benefits. It also has side effects. Please talk to your doctor for the full range of benefits and side effects and to ask any questions you might have.

## How does steroid treatment impact puberty?

- Steroid treatment can affect the timing and rate of puberty:
  - Puberty may start late, we call this *delayed puberty*
  - Puberty may not continue typically once it has started
- Compared to other males your age, you may be:
  - Shorter
  - Have little or no facial, body, or pubic hair
  - Have a smaller penis
  - Have a higher voice
- Puberty may start for you in your late teens or early 20's
- Your dose of steroid as well as the age you started steroid treatment may affect when you start puberty



**Steroid treatment may make you look younger than your peers but you still have the right to the same information about your body and puberty!**

## What does this mean?

- You will be shorter and may look younger than your classmates. Sometimes people might treat you like you're younger than you actually are.
- How you feel about how you look (body image) can impact how you think or feel about yourself as a person; your self esteem.
- You may not be interested in sexual expression at the same time your peers are. This is an individual experience. Whenever you are interested in sexual expression, it is a normal experience and something you can explore in a safe environment.
- You likely won't have to shave and will not get pimples when your peers do, but will experience this later when puberty starts.

## What can you do about delayed puberty?

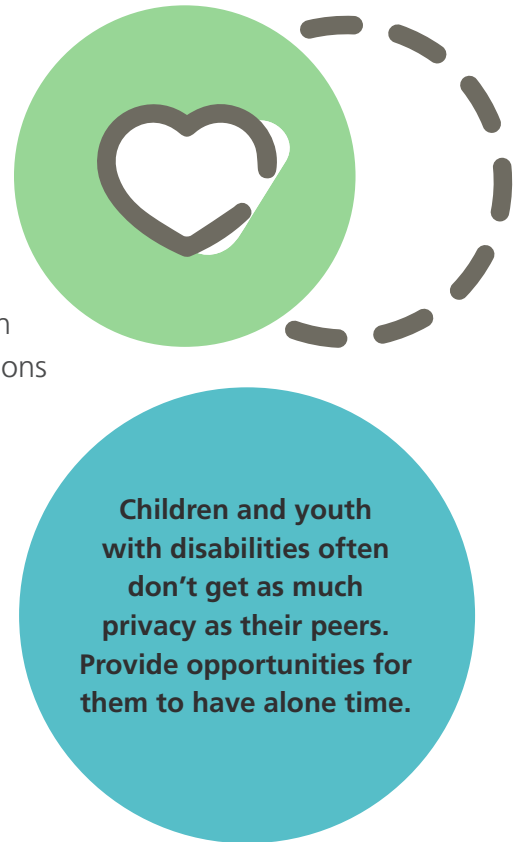
- Talk to your parents and your neuromuscular or family doctor.
- If there are no signs of puberty by the time you are 14 years old you can be referred to a doctor called an endocrinologist. This is a type of doctor that looks after puberty and bone health.
- An endocrinologist might prescribe testosterone, a male sex hormone that plays a key role in male puberty.
- Talk to your doctor about contraceptives if you are interested in becoming sexually active.

## Talking to your child about sex

**What?** Sexual health and expression is a very broad topic. You can lay the foundation for these conversations by using positive and anatomically correct language when describing body parts. Consent can start by explaining that it is okay to say “no” to being hugged or kissed by a relative or family friend.

**When?** Your conversations can start at a very young age with an age-appropriate level of information. Topics and depth of discussions can evolve over time. The earlier you start, the easier these conversations will be.

**Why?** Sexual health is a part of our overall health. It is an important part of your child’s life. Learning about their body and sexual expression is integral for their safety and wellbeing. Education is necessary for your child to make informed decisions about sex and relationships.



### How can you support your child to learn about privacy and boundaries?

- Provide opportunities for privacy. If you have a video/audio monitor or similar device in your child’s room, consider turning it off for predictable periods of time to promote your child’s privacy. This should be discussed with your child and they should be aware of when they have privacy.
- Engaging personal support workers (PSW)/attendants can provide an opportunity for your child to practice directing their care and setting boundaries.
- As your teen begins to explore sexual expression, PSWs can play a role by helping with set-up, positioning, and clean-up. This can be uncomfortable for teens to share with their parents.



## How can you support your child as they explore their sexuality and relationships?

Note: PSWs should not be present during sexual activities or exploration.

- Arm your child with factual information – direct them to resources (educational material or health care providers) if you don't feel comfortable talking directly about specific topics. Each family has their own set of values that shape perspectives on sexuality and relationships.
  - Health care professionals can talk to you directly, your child alone, or your family to answer any of your questions.
  - Your child has the right to discuss these topics with their health care provider and may choose to keep that information confidential from their parents.
  - Health care providers are obligated to report to authorities if they are concerned about imminent harm, including abusive/unlawful sexual relationships, neglect, and self-harm.
- Participation in a school-based physical education program with peers that includes health and sexual health is highly recommended.



### Resource

1. Muscular Dystrophy Canada – Let's Talk About Sex: A resource for parents 2013, <https://teachingsexualhealth.ca/app/uploads/sites/4/Sexual-and-Development-Disability-Guide-2016.pdf>



## Resources and additional reading

There are countless resources related to identity, gender, sexual expression, and disability. Some relevant resources are included below however there are many others. We are not endorsing any specific resources and encourage you to explore this thoughtfully. Please reach out to a trusted adult with any questions you have about what you see or read.

### General disability resources about dating, relationships, and sex

**A Quick & Easy Guide to Sex & Disability.** (2020) Andrews, A.

<https://www.comeasyouare.com/products/a-quick-easy-guide-to-sex-disability>

**Ability, relationships, sexuality.** SECCA. A range of unique resources including handouts and visuals to help people of all abilities learn and teach about relationships, sexuality, health, and rights.

<https://www.secca.org.au/resources/>

**The Bump'n blog:** a blog about all things sex, love, lust and disability.

<https://getbumpn.com/blogs/bumpn-podcast>

**Let's Talk Disability and Sex online hub.** Holland Bloorview Kids Rehab. A broad range of disability and sexuality related information and research with videos, infographics, and additional resources. [hollandbloorview.ca/sexuality](http://hollandbloorview.ca/sexuality)

**If I Knew Then What I know Now: A Transition to Adulthood.** Muscular Dystrophy Canada (2021). YouTube.

A panel of individuals with neuromuscular conditions talking about:

(1) sexuality, dating, and intimacy

<https://www.youtube.com/watch?v=mGX4xaoHt34&list=PLAk6GQXoqtAQjUOoj07Hpr0Qz0NG5spGH&index=4>

(2) women's health

<https://www.youtube.com/watch?v=WZTIWMwTO98&list=PLAk6GQXoqtAQjUOoj07Hpr0Qz0NG5spGH&index=6>

**Let's Talk Disability & Sex;** A Connection Day to Discuss Sexuality and Young People with Disabilities. Conference book. (April 28, 2021).

<https://hollandbloorview.ca/sites/default/files/2021-04/Let%27s%20Talk%20Disability%20%26%20Sex%21%20Event%20Booklet.pdf>

**Love, Dating, Relationships and Disability. Easter Seals.** Stories about dating, marriage, intimacy and friendships from people living with disabilities.

<https://www.easterseals.com/explore-resources/living-with-disability/love-dating-relationships-disability.html#dating>

## Teens, Sex and Neuromuscular Conditions: A Practical Guide

**Love Lounge.** Free advice on all things sex, love, and disability.

<https://enhancetheuk.org/sex-and-disability/>

**Queers on Wheels: The essential guide for the physically disabled LGBTQ community.**

Eva Sweeney (2010). A resource guide by a genderqueer disabled individual (Eva) for disabled people who want to explore their sexuality.

**SCI Sexual Health.** Spinal Cord Injury BC. Information and resources about sexual health created by sexual health clinicians and specialists in Vancouver, BC.

<https://scisexualhealth.ca/>

**“Setting Up for Solo Sex”** by Andrew Gurza and Angus Andrews in: *Bang! Masturbation for People of all Genders and Abilities* by Vic Liu (2021).

**SMA My Way: Your Canadian SMA Community.** Contributors share stories on topics that matter.

[www.SMAmyway.ca](http://www.SMAmyway.ca)

**The Ultimate Guide to Sex and Disability** by Miriam Kaufman, Fran Odette, and Cory Silverberg (2007).

## Sexual health resources

**Building Consent Castles.** Everyday Feminism. A graphic explaining ongoing consent.

<https://everydayfeminism.com/2016/07/metaphor-for-consent/>

### Canadian Centre for Child Protection

- Online safety (<https://www.protectchildren.ca/en/resources-research/online-safety/>)
- Programs and initiatives (<https://www.protectchildren.ca/en/programs-and-initiatives/>)

**How Do You Know If Someone Wants to Have Sex With You?** By Planned Parenthood.

A video describing common situations and how to interpret/respond.

<https://youtu.be/qNN3nAevQKY>

**Online dating safety tips.** Kids Help Phone. (2021)

<https://kidshelpphone.ca/get-info/online-dating-safety-tips>

**Preventing Pregnancy,** Kids Help Phone.

<https://kidshelpphone.ca/get-info/preventing-pregnancy-info-about-birth-control-safer-sex/>

**Preventing STIs,** Kids Help Phone.

<https://kidshelpphone.ca/get-info/preventing-stis-info-about-protection-safer-sex/>

**Sexual Health Ontario.** Telephone or e-chat service for asking general questions about sexual health with a sexual health expert

<https://sexualhealthontario.ca/en/chat>

## Holland Bloorview

Kids Rehabilitation Hospital

**Wondering About Birth Control?** City of Toronto. This is a resource with information about how to prevent pregnancy.

<https://www.toronto.ca/wp-content/uploads/2018/10/8e49-Wondering-About-Birth-Control-2018-AODA.pdf>

**Wondering About STIs?** City of Toronto. This is a resource with Information on Sexually Transmitted Infections.

<https://www.toronto.ca/wp-content/uploads/2018/05/97cf-tph-wondering-about-stis.pdf>

## Sexual health and disability services

**EdgeWest.** Accessible and inclusive sexual health education for youth.

<https://www.allianceon.org/EdgeWest>

**Sexual Health Rehabilitation Service.** G.F. Strong. Vancouver Coastal Health. Sexual Health Clinicians trained in sexual health, disability, and rehabilitation.

[http://www.vch.ca/Locations-Services/result?res\\_id=871](http://www.vch.ca/Locations-Services/result?res_id=871)

**Vibrant Healthcare Alliance.** Offers a Sex and reproductive health workshop for youth and adults with mobility-related disabilities, as well as a youth health clinic that is accessible for individuals with physical disabilities.

<https://www.vibranthealthcare.ca/health-promotion-prevention/>

## Caregiver and parent resources

**Ability, relationships, sexuality.** SECCA. A range of unique resources to help people of all abilities learn and teach about relationships, sexuality, health, and rights.

<https://www.secca.org.au/resources/>

**Dating and intimacy.** Talking About Sexuality in Canadian Communities (TASCC).

<https://tascc.ca/supporting-youth-with-disabilities/dating-intimacy/>

**Let's Talk Disability and Sex Online Hub.** Holland Bloorview Kids Rehab. A broad range of disability and sexuality related information and research with videos, infographics, and additional resources.

[www.hollandbloorview.ca/sexuality](http://www.hollandbloorview.ca/sexuality)

**Get the Facts on Sexual Health – For Parents.** Planned Parenthood. Resources geared toward parents on general topics such as identity, pregnancy, relationships, and sex.

<https://www.plannedparenthood.org/learn/parents>

**How to Talk About Sex & Relationships With A Special Needs Child.** Sterland, E. (2013)

<https://friendshipcircle.org/blog/2013/03/18/how-to-talk-about-sex-relationships-with-a-special-needs-child>

**Let's Talk About Sex: A resource for parents.** Muscular Dystrophy Canada (2013) – <https://muscle.ca/wp-content/uploads/2019/09/SexualityParentGuide13-EN.pdf>

**Sexuality Education for Students with Disabilities.** Center for Parent Information & Resources. (2018) <https://www.parentcenterhub.org/sexed/>

**Talking to your children about sexuality.** Sexuality and Disability. Alberta Health Services (2016) <https://teachingsexualhealth.ca/app/uploads/sites/4/Sexual-and-Development-Disability-Guide-2016.pdf>

**Teen Learning Hub.** About Kids Health. Considerations and resources about mental health, puberty, relationships, & sexuality, etc. <https://www.aboutkidshealth.ca/yourteen>

## Workshops and learning

**Crippling up Sex with Eva.** An author and sex educator focused on sex and disability. Offers consultations, classes, workshops, sex toy review and sales. <https://www.cripplingupsexwitheva.com/>

**EdgeWest Healthcare for Youth.** Accessible and inclusive sexual health education for youth. <https://www.allianceon.org/EdgeWest>

**Extend a Family – Sexuality Workshop with a Focus on Healthy Relationships.** Located in Toronto, this is a workshop series focused on foundational skills for healthy relationships geared toward individuals 11-15 years of age with developmental disabilities, with the ability to incorporate information on physical disabilities. <https://www.extendafamily.ca/sexuality-and-healthy-relationships>

**Get the Facts on Sexual Health – for Teens.** Planned Parenthood. Resources on sexual health, LGBTQ, gender, going to the doctor, bullying, etc. <https://www.plannedparenthood.org>

**GF Strong Rehabilitation centre.** Vancouver Coastal Health. Sexual health youth clinics have Sexual Health Clinicians and a Sexual Health Doctor with knowledge in sexual health, disability, and rehabilitation. In-patient and out-patient programs are available. [http://www.vch.ca/Locations-Services/result?res\\_id=871](http://www.vch.ca/Locations-Services/result?res_id=871)

**Good For Her.** Located in Toronto, a resource for people of all genders, sexes, orientations and desires. Offers a variety of sex toys, workshops, advice, and sex therapy (many are available online). Not an accessible environment. <https://goodforher.com/>

**SECCA, Ability, relationships, sexuality.** A range of unique resources to help people of all abilities learn and teach about relationships, sexuality, health and rights.

<https://www.secca.org.au/resources/>

Look for a **sex therapist in your community**, or someone who will see you online (professionals typically must be licenced in the provinces or territories where they work).

**Vibrant Healthcare Alliance.** Offers a Sex and reproductive health workshop for youth and adults with mobility-related disabilities. <https://www.vibranthealthcare.ca/health-promotion-prevention/>

**Thrive Rehab.** An Australian resource that provides sexual health consultations to individuals, health professionals and organizations.

<https://www.thriverehab.com.au/>

## Tools and toys

*There are many stores that can be visited in person and online to explore tools and toys for sexual expression. A few inclusive options are included below; however, based on your preferences and region, there may be stores closer to home you can explore.*

**The Bump'n Joystick.** An accessible toy created for people with hand limitations

<https://getbumpn.com/collections/shop>

**Come as You Are.** Located in Toronto, a resource for toys, books, and information.

Wheelchair accessible.

<https://www.comeasyouare.com/>

**Dallas Novelty.** American sales site, specializing in disability and sexuality, with lots of positioning tools.

[www.dallasnovelty.com](http://www.dallasnovelty.com)

**EazyHold Universal Cuff.** Used to help hold objects, including toys for sexual expression.

<https://www.performancehealth.ca/eazyhold-universal-cuff>

**FDMT.** For wedges and rolls for positioning tools.

<https://www.fdm.ca/en>

**Flaghouse.** For wedges and rolls for positioning tools

[www.Flaghouse.ca](http://www.Flaghouse.ca)

**Good For Her.** Located in Toronto, a resource for people of all genders, sexes, orientations and desires. Offers a variety of sex toys, workshops, advice, and sex therapy (many are available online). Not a wheelchair accessible environment.

<https://goodforher.com/>

## Teens, Sex and Neuromuscular Conditions: A Practical Guide

**Handy Lover.** French manufacturer and sales, for sexuality and mobility, positioning/adapted tool.  
<https://handy-lover.com>

**Liberator Shapes.** Foam positioning pillows available in a variety of shapes (wedge, ramp, rocking, etc.)  
<https://www.liberator.com>

### Gender and sexual orientation resources

**Coming Out.** Graphic. Killerman, S and Bolger, M. (2018)  
<https://www.itspronouncedmetrosexual.com/downloads/Safe%20Zone%20Project%20Coming%20Out%20Handout%20by%20Sam%20Killermann%20and%20Meg%20Bolger.pdf>

**Let's Talk Disability and Sex online hub.** Holland Bloorview Kids Rehabilitation Hospital (2022).  
[www.Hollandbloorview.ca/sexuality](http://www.Hollandbloorview.ca/sexuality)

**Gender-Diverse and Transgender Children.** Rafferty, J. (2021).  
<https://www.healthychildren.org/English/ages-stages/gradeschool/Pages/Gender-Diverse-Transgender-Children.aspx>

**Genderbread Person.** Killermann, S.  
<https://www.samkillermann.com/work/genderbread-person/>

**LGBTQ2S+ Terms to Know.** Toronto Pflag.  
<https://www.torontopflag.org/lgbtq2s-terms-to-know>

**Meet the sexualitree.** Killerman, S and Rayne, K. A model for thinking about and exploring the ways we do (or do not) experience sexuality.  
<https://www.samkillermann.com/work/sexualitree/>

**Queers on Wheels: The essential guide for the physically disabled GLBTQ community.** Eva Sweeney. (2010). A resource guide by a genderqueer disabled individual (Eva) for disabled people who want to explore their sexuality.

**Sex, Gender, and Sexual Orientation: An Overview.** Sick Kids. (2021)  
<https://www.aboutkidshealth.ca/Article?contentid=3965&language=English>