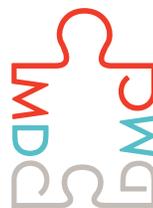


Teens, Sex and Neuromuscular Conditions:

A Practical Guide for Clinicians

Holland Bloorview
Kids Rehabilitation Hospital



MUSCULAR
DYSTROPHY
CANADA
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CANADA

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How to use this guidebook

Download and save the interactive pdf to access all media links. The [blue](#) text in this document indicates a link that you can click on for additional information.

Navigate through the pages by clicking on arrows at the bottom of the page.

This PDF version is accessible for screen readers and other accessible technologies.



Introduction

This resource is intended to be a practical guide for healthcare professionals (HCPs) focused on the needs and wellbeing of teens with neuromuscular conditions/disorders (NMDs) who have goals related to sexual health and expression.

This guidebook is not intended to provide comprehensive sexual health education; and resources for further learning have been provided where appropriate. While sexual health and expression can be challenging for many health care providers to discuss with their clients, it is nonetheless an important and integral part of health care. By addressing your clients' goals related to sexual health and expression, you will also be working to decrease the stigma (both internalized and societal) that individuals with neuromuscular conditions experience related to sex.

While this guide is written by occupational therapists (OTs), it is intended for all health care providers and was informed by a variety of health professions including social work, ethics, speech language pathology, medicine, and youth facilitators. As always, it is essential to work within the scope of your practice and knowledge base. If parts of this guidebook fall outside of a professional scope, readers are encouraged to connect clients to appropriate clinicians who can support goals related to sexual expression.

The content in this guide has been created by researching and summarizing scientific and grey literature and resources, and consulting with individuals with lived experience of disability, health care providers, and researchers. When required, existing sexual education or general disability information was adapted using an OT/neuromuscular care lens to inform sexual health practices for youth with neuromuscular disorders. Many topics covered in this guidebook have complimentary handouts that can be reviewed and shared directly with the teenagers you work with and their families.

We recognize that concepts, language, and practices evolve over time and some of the information contained in this guidebook will quickly require updating. We encourage ongoing education on the various topics contained in this book and hope that it serves as a springboard to incorporating sexual health more consistently into the care of youth with neuromuscular conditions.

Why talk about sexual expression with teens and young adults who have NMD?

According to the Ontario Ministry of Education sexual health curriculum, conversations around sexuality begin in grade 1 with discussing anatomy¹. Sexual expression is introduced into the curriculum in grade 7, where topics including sexual health and contraception options for safe sex are explored¹. Sexual health is a human right. It is important to introduce the topic of sexuality at an early age, and age/grade milestones can help to guide topic selection. Health care professionals must exercise their clinical reasoning in deciding when to start these discussions, and with what content.



Factors you can consider in deciding when and how to address the topic of sexuality might include:

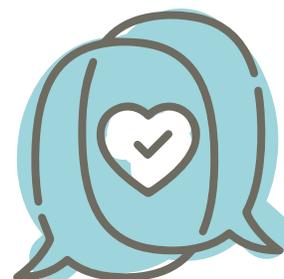
- your client is expressing an interest;
- your client is experiencing delayed puberty;
- client age and developmental level;
- whether you are speaking to your client alone or with their caregiver(s).

Many adolescents with disabilities lack the knowledge and education necessary to develop a healthy sexual identity which increases their vulnerability and risk for sexual abuse, sexually transmitted diseases, and unwanted pregnancies^{2,3}. Sexual health education has been found to reduce experiences of violence in dating and intimate relationships and to promote healthy relationships⁴. Therefore, it is essential to provide sexual health education to adolescent clients with disabilities to promote healthy sexual expression and reduce risk of abuse and exploitation.

Additionally, there is significant societal stigma, internal stigma, and biases around sex and disability. It is important to examine and reflect on any internalized biases you may hold around the topic of sex, relationships, and disability – individually, as well as together. You will see that this is one of the first steps in the [Ex-PLISSIT](#) model. By normalizing conversations around sex and disability with your clients and their families you can support the removal of stigma around this topic.

Your role in addressing sexual expression

Most health care practitioners can play a role in supporting their clients' sexual health and expression. Health care teams and services vary across Canada. Depending on the structure of neuromuscular services where you practice, your role related to sexual expression might look different. As with any treatment approach, your scope and role will also be shaped by your regulator and your level of competency in this practice area. Physicians can address medication questions related to sexual performance and the impact of medications, social workers can help with building meaningful relationships, nurses can provide education on contraceptives, and so on. Physiotherapists and OTs bring a strong knowledge base related to positioning, energy conservation, and mobility. OTs are also skilled at supporting development of compensatory strategies to support participation in client goals related to sexual activities, and task or tool adaptation⁵. These goals might include planning for dates, managing hair, make-up, or considering accessibility of a restaurant or bar, in addition to goals directly related to sexual activities. There are many other team members that may be involved in supporting these goals (e.g. psychology, therapeutic recreation, youth/peer facilitators). Relationships, friendships, and sexual expression are complex and will benefit from a team approach.



Things you need to know when addressing sexual expression



Privacy and confidentiality in your practice

Each health care professional is expected to uphold the standards for practice set by their regulatory body, organizational policies, and provincial laws regarding privacy and confidentiality of client's personal health information (PHI). Topics around sexuality may be difficult to discuss with your client if caregivers are present. Thoughtful documentation of private conversations with your client is required if caregivers have access to the health record. Conversely, a caregiver may wish to speak with you about sexual health information that they want to keep private from your client. Documentation practices and access should be considered and established in advance to ensure confidentiality is maintained.

Considerations for consent to healthcare related to sexual expression

Informed consent is obtained when a capable individual understands the information surrounding PHI and treatment, and appreciates the foreseeable risks of their decision or lack thereof⁶. Healthcare professionals should continuously obtain consent since consent can change and be withdrawn at any time, and capacity can change⁶. A client may be capable of consenting to discussions regarding writing aids but not to discussions about sexual expression. Legislation regarding what age individuals are legally able to consent and make decisions regarding their health care differs across provinces and territories. A summary is included below based on legislation in 2022; however, you are responsible for ensuring this information is accurate as it may change over time (see table below).

| Province/ Territory | Legislation regarding age of consent to health care |
|------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| British Columbia | <p>The <i>Health Care (Consent) and Care Facility (Admission) Act</i> states that all individuals 19 years and older are presumed to be capable until otherwise demonstrated.</p> <p>For individuals under 19 years of age, The <i>Infant Act</i> states that minors can provide consent if capacity is demonstrated. Consent is only valid if health care professionals have also made reasonable efforts to ensure treatment is in the minor's best interest.</p> |



| Province/ Territory | Legislation regarding age of consent to health care |
|---------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Alberta | An individual under 18 years of age is assumed to be without capacity. An individual under 18 years can be assessed for capacity and can be deemed a “mature minor” and can then give consent to, or refuse, healthcare decisions. |
| Saskatchewan | An individual under 18 years of age or older who is assessed and deemed capable can provide consent to, and make, treatment decisions. |
| Manitoba | Individuals 16 years of age or older are presumed capable to make health care decisions. Individuals under the age of 16 years can provide consent if they are assessed and deemed capable. |
| Ontario | The <i>Health Care Consent Act</i> states that all individuals are presumed capable of making health care decisions. The <i>Substitute Decisions Act</i> states that individuals 16 years of age or older are capable of giving or refusing consent for health care decisions, unless reasonable grounds to believe otherwise. |
| Quebec | Parental consent is required for individuals under 14 years of age. An individual 14 years of age or older can consent to care. However, parental consent is required for care that is not essential if the care poses a serious risk to health or can have serious or permanent side effects. |
| New Brunswick | The <i>Medical Consent of Minors Act</i> states that individuals who are 16 years of age and older can consent to health care decisions. Individuals younger than 16 may provide consent if they are capable of understanding the consequences of treatment, and their decision is consistent with their best interests health wise. |
| Nova Scotia | The age of majority is 19 years old. There is no stated age of consent for health care decision making. |
| Prince Edward Island | Every individual, including those under 18 years of age, may give or refuse consent for health care decisions if they are deemed capable. |
| Newfoundland and Labrador | The <i>Advanced Health Care Directives Act</i> states that individuals 16 years of age or older are presumed to be capable to make health care decisions. Individuals younger than 16 can make health care decisions if assessed and deemed capable. |
| Yukon | Every individual, including those under 19 years of age, who are presumed capable can give or refuse consent to care. |
| Northwest Territories | The age of majority is 19 years old. There is no stated age of consent for health care decisions. |
| Nunavut | In the <i>Guardianship and Trusteeship Act</i> , an individual 18 years of age or older is presumed to be capable of making health care decisions. |



Considerations for client consent for sexual activity

The legal age of consent for sexual activity in Canada is different from the age of consent to healthcare decisions (see [Considerations for consent to healthcare related to sexual expression](#) section). An individual may have the capacity to consent to a treatment decision but may not meet the legal age of consent for sexual activity. In Canada, individuals must be at least 16 years old to provide consent to sexual activity⁸. This law applies to all types of sexual activities including kissing and fondling⁸. All non-consensual sexual activities regardless of age are criminal offences. However, there are close-in-age exceptions to the legal age of consent:

1. An individual who is 14 or 15 years old can provide consent to sexual activity if:
 - (a) The sexual partner is less than 5 years older than the individual⁸ and
 - (b) No relationship of trust, authority or dependency or any other exploitation of the young individual exists⁸.
2. An individual who is 12 or 13 years old can provide consent to sexual activity if:
 - (a) The sexual partner is less than 2 years older than the individual⁸, and
 - (b) No relationship of trust, authority or dependency or any other exploitation of the young individual exists⁸.

In cases where there may be a power differential present, the legal age of consent is higher. A 16- or 17-year-old cannot consent to sexual activity if:

- (a) The sexual partner is in a position of trust or authority towards them⁸.
- (b) The young person is dependent on the sexual partner⁸.
- (c) The relationship between the person and their partner is exploitative⁸.

Power differentials exist in caregiving relationships such as teachers, bus drivers, personal support workers, attendants, and within families. It is important for your clients to be aware that if a person in a position of power is touching them in a sexual manner, they need to tell a trusted adult.

Duty to report

Under Canadian child welfare laws, everyone has a duty to report child abuse⁹. Child abuse is defined as “the physical or psychological mistreatment of a child by an adult”, and includes sexual abuse⁹. Across all Canadian provinces and territories, children with disabilities are eligible for protective services up until the age of 19 years old⁹.

Gender expression and sexual orientation

Increasing your understanding of language around gender and sexual orientation will promote inclusive conversations with your clients when supporting goals around sexuality and relationships. Implicit biases present in the general population have been found to exist at a similar rate amongst healthcare providers and can include biases related to race, age, and gender¹⁰.

The frequent assumption of heterosexuality and the gender binary (man/woman) is a fundamental problem in healthcare institutions¹¹. It is incumbent upon each health care practitioner to work to undo these biases and counteract existing inequities.

We acknowledge that these topics contain much more depth and nuance than we have space to dedicate in this handbook. We encourage clinicians to explore the [resources](#) section of this guidebook for additional information, and to refer clients to appropriate organizations with the requisite expertise. We also acknowledge that language and concepts evolve over time. Staying connected to resources is important for providing knowledgeable and inclusive care.

A helpful resource for educating yourself on the way that society has constructed gender is Sam Killermann's Genderbread Person¹² (included on the next page). This resource is not copyrighted and has a number of helpful additional resources on the website, including ways to approach teaching about gender, if that is a part of your role. Killermann also offers resources on sexual orientation, and coming out¹³ (see [Resources and additional reading](#) handout).

While gender identity and expression, sex assigned at birth, and sexual orientation intersect, they are independent of one another and should not be conflated.

Gender identity is separate from sex assigned at birth. **Sex assigned at birth** is the decision that a physician made based on their interpretation of an individual's genitalia when they were born. **Gender identity** is how a person feels in their body and does not necessarily align with their sex assigned at birth. Medical charts often include sex assigned at birth. Some facilities are creating space for clients to indicate their gender identity within the chart.

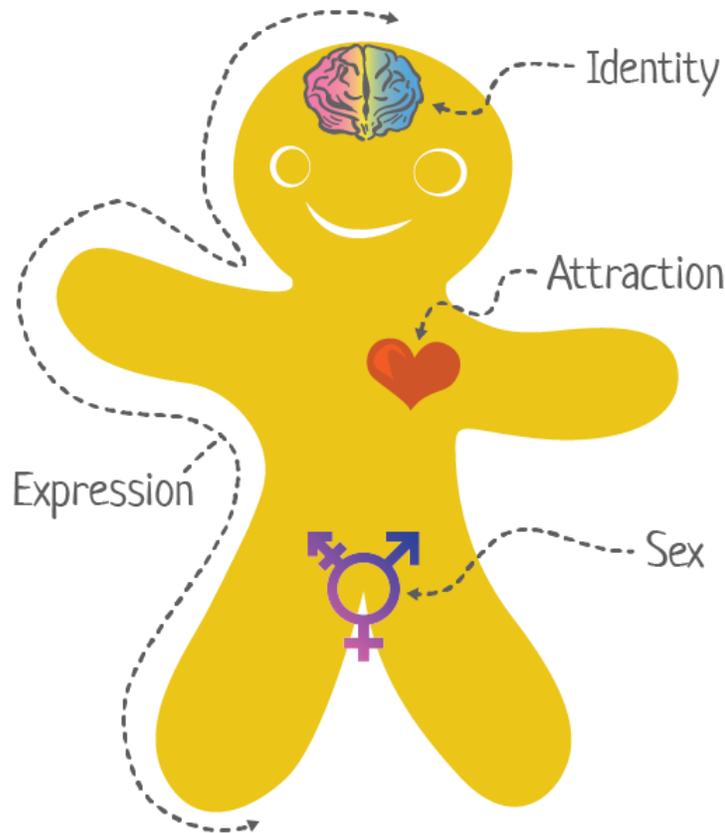
Sexual orientation refers to who a person is attracted to sexually, spiritually or, emotionally¹⁴. Sexual orientation can be stable or fluid.

Coming out is when an individual becomes aware of, and identifies, their sexual orientation and chooses to tell someone else¹³. This is not a distinct event, but occurs each time they tell a new person. It is a person's right to choose to tell, or not tell, others about their sexual orientation. It is important to be mindful that your client may come out to you but not to others on your team or in their lives. Clarify what language they would like you to use in different situations.

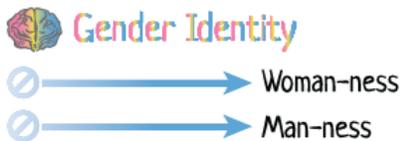


Image 1: Killermann's Genderbread Person¹²

The Genderbread Person v4 *by its pronounced METROsexual.com*

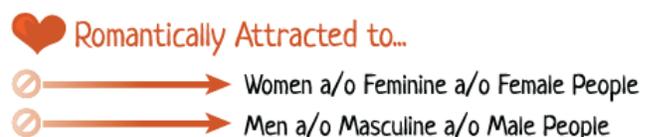


⊘ means a lack of what's on the right side



Identity ≠ Expression ≠ Sex Gender ≠ Sexual Orientation

Sex Assigned At Birth
 Female Intersex Male



Genderbread Person Version 4 created and uncopyrighted 2017 by Sam Killermann

For a bigger bite, read more at www.genderbread.org



There are many other terms that are important for you to know when talking about gender and sexuality. This language is constantly evolving but some common terms that you may want to familiarize yourself with are: **queer, straight, gay, intersex, two-spirit, pansexual, transgender, non-binary, bisexual, asexual, gender expression.**

As noted above, this topic deserves more time than we can dedicate here – You can find more information about sexuality, disability and identity in the free and accessible book ‘Becoming You: Exploring sexuality and identity for pre-teens.’ This is one of the many resources available on the [Let’s Talk Disability and Sex online hub](#). The hub includes resources for HCPs, youth, families and others to help conversations about sexuality and disability.¹⁵



How can you support gender and sexual orientation with your clients?

When introducing yourself and your role cues can be used to communicate “permission” for clients to speak about their identity, gender expression, and sexual expression (See [EXPLISST](#) model). Cues can include:

- wearing a rainbow flag on your name tag;
- sharing your pronouns;
- using the name and pronouns disclosed to you by your client;
- never assuming someone’s gender or sexual orientation;
- familiarizing yourself with basic LGBTQ2+ terms;
- having sexuality friendly posters in treatment spaces that are inclusive of the variety of intersections of gender and sexuality. www.RainbowHealthOntario.ca has some examples¹⁶;

Throughout the course of your therapeutic relationship, other strategies you can use are:

- engaging in conscious consideration of the language you use when writing client reports, documentation, and communicating results of standardized tests;
- awareness that your client may come out to different people in their lives at different times. It may be relevant to engage in discussion with your client about how they would like you to refer to them alone and around others;

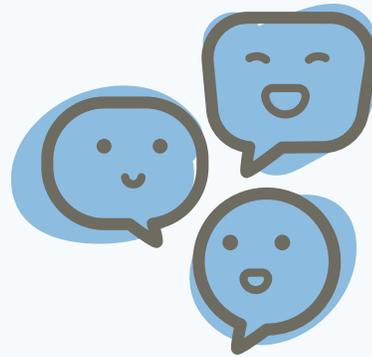


How can you support gender and sexual orientation with your clients? Continued

- extra care should be taken with documentation;
- acknowledge and follow through on requests from clients to be called a different name, or referred to with different pronouns than what is documented in their health chart;
- with consent, update pronouns and names in the health chart if this is possible.

Organizations can also work to create an inclusive environment by:

- reviewing your interview questions to ensure they are gender and sexual orientation inclusive.
- modifying existing forms and templates to be inclusive;
- having sexuality friendly posters in treatment spaces that are inclusive of the variety of intersections of gender and sexuality;
- developing processes for updating pronouns and chosen/preferred names in health charts.



Consider who has access to online medical records and how this might impact what information and names/pronouns are included based on your client's preference.

How to talk to teens about sexual expression: The Ex-PLISSIT model

The Ex-PLISSIT model is an extension of the PLISSIT model, a framework that can act as a guide for introducing sexuality into your clinical interactions¹⁸. This model may be beneficial in guiding conversations about sexual expression and related interventions with teens who have NMDs. We encourage you to refer to the Ex-PLISSIT model as you use this guide to support conversations about sexual expression. The Ex-PLISSIT model is described briefly here, and there are many resources related to it if you want more information.

- Ex-** The *extension* to the PLISSIT model emphasizes that permission-giving by clients is essential at each stage and encourages HCPs to engage in reflective practice to increase self-awareness and challenge assumptions or biases¹⁸.
- P** The first stage is *permission-giving* in which HCPs give clients the opportunity to express their needs or concerns about sexuality¹⁸. Including sexuality and relationships when listing possible topics to discuss with your client is one way to do this.
- LI** The second stage is *limited-information*, where education is provided about the possible impact of a client's condition on sexual function¹⁸. This could include education or strategies for compensating for fatigue, muscle weakness, or limited range of motion.
- SS** The third stage is *specific suggestions* in which solutions specific to a client are offered to enhance participation and engagement¹⁸. You may be able to address your client's specific goals individually or as a team.
- IT** The fourth stage is *intensive therapy* where resources can be provided to your client for referral to further therapy services or experts¹⁸.

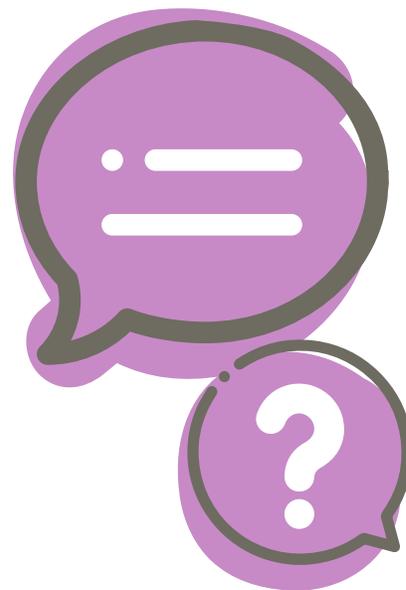
Ok, so now what? Conversation starters about sexual expression

Some health care professionals may find it difficult to initiate conversations about sexual expression with clients. Here are some prompts that may be helpful as you develop more comfort with this topic:

- Have you thought about dating? Are you interested in dating?
- Some of the things we could talk about today are [school, going out with your friends, dating, sexuality....]
- Do you have any questions about your body or exploring your body?
- As you start to get ready for life after high school, do you have any questions about [living on campus; having friends over to your residence room; safe sex]?
- Provide brochures or handouts about initial topics for consideration (e.g. consent, friendships and relationships).

You can find more sentence starters for healthcare professionals on the [Let's Talk Disability and Sex online hub](#).

Talking to clients about consent in relationships and for sexual expression



Consent is given when an individual voluntarily agrees to participate in, or perform, a task. Individuals must provide and obtain consent prior to participating in physical touching or sexual activities, including texting and online activities, with other individuals. You can inform your clients about the importance of obtaining and providing consent to sexual activities. An understanding of consent is an essential building block for readiness to participate in sexual activities.

Age of consent to sexual activity in Canada

This topic was addressed earlier in this resource. Please see the [appendix](#) section for more information.

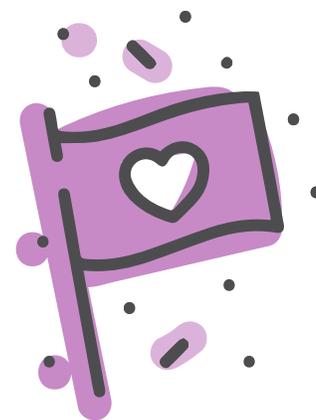
Consent is not the absence of “no”

There are many resources about understanding consent and verbal communication of consent so we will not reiterate those here. Instead, we will focus on the considerations specific to NMDs.

For some individuals with NMDs, verbal communication may be a relative strength. Others may use non-verbal, augmentative, written, or other forms of communication. Advance discussion to establish clear methods for communicating consent before and during activities related to sexual expression is strongly encouraged. There may be a role for you to engage in discussion with your clients about how they will establish and maintain consent with a partner. A team-based approach, and your knowledge of NMDs can be used to help your clients establish effective and consistent strategies for communicating consent in different situations.

Given that individuals with NMD have different physical abilities, some factors to consider when discussing expressions of consent are:

- Some of your clients will communicate consent verbally such as requesting or directing a partner to participate or stop before or during sexual activities (i.e. “Put your hand here”; “I don’t like that, stop now”).



- Your clients with significant muscle weakness may not be able to use body language to initiate or turn away.
- Some of your clients may not have clear speech; they may use sounds, nodding/shaking of head, eye gaze, or facial expression, or written/augmentative communication.
- Some neuromuscular conditions affect the muscles in the face, making it difficult to smile or show dissatisfaction through facial expressions.
- Some additional condition-specific information can be found in [Appendix A](#).



Additional information to support teaching consent can be found in the client handout [Consent and relationships](#).

Consent is an ongoing, iterative process

It is important for your clients to understand that consent is a continuous, dynamic experience both for themselves, and for their partners. You can provide scenarios and/or resources about ongoing consent to support your clients as they navigate this topic. For example, an individual may have discussed and agreed to an activity during online chats or phone discussions, but at the time of their date they may no longer feel comfortable and can revoke consent at any time.



There are helpful resources (including links to videos) to supplement discussions with your clients around the nuances of ongoing consent on the [Resources and additional reading](#) handout. While this concept is not unique to individuals with NMD, given that individuals with disabilities are at high risk of sexual abuse and victimization, it is important that they are aware of their rights when engaging in sexual activity.



Friendships and relationships

Depending on your role on your team, friendships and relationships may be a core part of your practice and this section can serve as a review. Whether this is a topic you address often or rarely, we can all appreciate that everyone needs friends. Youth with NMDs have identified social participation as a priority¹⁹. Individuals with Duchenne Muscular Dystrophy (DMD) over 10-12 years of age have lower participation in activities, including social activities compared to their peers^{20, 21, 22, 23}. The benefits of social connectedness are well-known and social support has been identified as the strongest contribution to resilience in boys with DMD²⁴. While there is limited formal research about social connection and youth who have other NMDs, we expect there would be similar benefits.



Bullying is an unfortunate reality for many youth with disabilities. Statistics Canada (2017) reported 42% of youth with a disability experienced bullying in school, which increased to 62% for youth with a severe disability²⁵. Early and regular screening for signs of bullying in medical visits was recommended in a recent study of youth with NMDs who have experienced bullying²⁶. While there is not one easy solution for these social challenges, this resource includes strategies for you to initiate conversations with your clients about addressing bullying, building and maintaining friendships and relationships.

Talking about friendship and relationships

Talking to clients about friendships and relationships can be challenging. Sometimes it is hard to hear that your client doesn't have friends, or feels excluded from peer groups. However, initiating this conversation creates opportunities for them to identify goals and barriers to their participation.



What can you do to support discussion about friendships, relationships and bullying?

- Add questions about friendships, relationships, and bullying to your standard interview questions.
- Ask your clients what they like to do for fun, and who they do it with.
- Build awareness of your own comfort and biases. Consider how this impacts your conversations with clients around friendships, relationships, and bullying.
- Support clients to find new or different ways to participate in meaningful activities. Individuals with NMDs may require modifications to activities to participate. The need for, and type of, adaptations may change over time, particularly with progressive conditions.

What can you do to support discussion about friendships, relationships and bullying? Continued.

- Collaborate with specialists to support your clients to problem solve and identify unique and creative solutions for participation. Occupational therapists, therapeutic recreation specialists, and physiotherapists can be great partners to work with your clients to modify activities.
- Support your clients to:
 - Identify and explore their interests.
 - Join clubs in school or outside of school.
 - Reach out to peers with similar interests.
 - Participate in activities that are “just” for fun!
 - Provide coaching around interactions with peers and having conversations.
 - Talk about rejection. Rejection is a natural experience in both platonic and romantic relationships. Building and maintaining relationships takes practice.
- Support to identify and manage bullying behaviours your client may be experiencing at school, online, or at home. This may include:
 - Discussion around acceptable joking vs teasing.
 - Identifying strategies to report and manage bullying.
 - Referral to resiliency programs²⁶.
 - Presentations at the start of the school year to educate peers²⁶. Some clients like to present themselves, while others might seek support from external organizations.



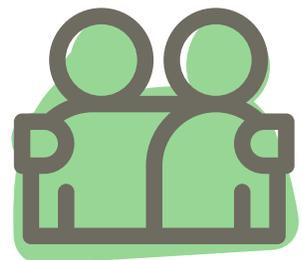
Muscular Dystrophy Canada can provide “Muscle Fact Presentations” to educate school-aged youth about the impact of neuromuscular conditions²⁷.

There are social skills workshops and coaching programs that you might consider referring your clients to, as needed. Connect with colleagues in your region who work in this area as they will have the most up-to-date and relevant information to direct you to resources.

Talking about romantic relationships, dating, and sexual activities

Sexual satisfaction and healthy relationships are indicators of better physical and mental health²⁸. Individuals with disabilities want to have conversations with professionals about more than contraception and sexually transmitted infections. There are other sections of this book that address physical accommodations and practical suggestions related to sexual expression. This section is dedicated to guiding you through conversations related to romantic relationships, dating, and sexual health.

Be inclusive by using gender neutral language when asking questions about dating and relationships.





What can you do to support clients with romantic relationships and dating?

- Add questions about friendships, dating, and sexual expression to your standard interview questions. This will show your clients that relationships and sex are acceptable topics to talk about, and valued parts of their lives.
- Ask explicit questions, such as “Are you dating or in a relationship?” or, “Are you interested in dating or being in a relationship?”
- Consider development of social skills, including groups and workshops in your community.
- Have conversations with clients about their values (cultural, family and personal) and boundaries.
- Provide coaching related to consent (see [Talking to clients about consent in relationships and for sexual expression](#) in the guidebook, and the handout).
- Collaborate with clients to determine what sexual expression means to them.
- Work with your clients, and their team (as appropriate), to help them develop strategies to communicate with potential partners. Speech and facial expression can be impacted by some NMDs. Individuals with these conditions will benefit from explicit reciprocal communication strategies with a partner regarding consent, pleasure, and preference. (See [Talking to clients about consent in relationships and for sexual expression](#) section above).
- Encourage your clients to participate in the health portion of physical education classes with their peers for sexual health education and related topics covered in the curriculum.



The [Friendships, relationships, and dating handout](#) can be used as a tool to initiate conversations with your clients.

Talking about online activities

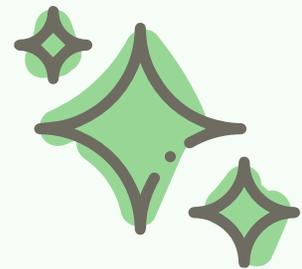
Kids and teens communicate regularly online, through texting, video games, and apps. While communicating with peers is encouraged, extra care is required when chatting online with people they have and haven't met in person. Your clients should be informed of the risks of sharing personal information, photos, or other media. Clients will benefit from strategies and resources to protect themselves when interacting or building relationships with others online. There are many existing resources to guide you and your clients in this regard. Websites, such as Kids Help Phone and the Canadian Centre for Child Protection have free resources including online safety lessons (see [Resources and additional reading](#) handout).





What can you do to support clients with goals related to sexual activities?

- Build awareness of your own comfort and biases; consider how this impacts your conversations with clients around friendships, relationships, and sex.
- Normalize interest in sexual expression, and provide a judgement-free environment for sexual and relational support. Ask explicit questions, such as “Do you want to learn about sex, exploring your body, or masturbation?” “Do you have questions about your body?”
- Support your clients to advocate for privacy at home. Individuals with physical disabilities have reported they don’t have enough privacy²⁹. Many parents use video, audio, or baby monitors in their child’s room to support with their care. However, this does not allow for age appropriate privacy for socializing, self-exploration, or sexual expression with a partner. There are many call bell options that will meet your clients’ care needs and will also allow them to have more privacy.
- Work with your clients to explore what sexual expression means to them. This can include (but is not limited to) texting with a peer, flirting, watching a movie, looking at pornography, thinking about something exciting, self-exploration, or intercourse.
- While looking at pornography is normal, it is important for your clients to be aware of risks and legal limitations.
- Problem solve with your client to help them explore sexual activities. This guidebook has some practical resources that may be useful for these conversations.
- Discuss the role of personal support workers (PSW) or attendant care in sexual expression. PSWs may play role in set-up for sexual activities (e.g. positioning, managing clothing, set-up, and/or clean-up)²⁹.



Additional information on safe sex practices can be found within the [Sexual expression and staying safe handout](#).

Talking to clients about accessing accurate information and support related to sexual expression

Teens are accessing information about sexual health and expression from a variety of sources. Not all resources are accurate or up to date and as a result, teens may not be accessing accurate or reliable information. Friends, peers, and siblings are commonly consulted for this information but can often reinforce myths or misunderstandings.

Education around sexual health and expression is an important tool in promoting healthy relationships and preventing harm⁴. As a health care professional, you can promote discussion by providing a safe environment for clients where they can speak freely about relationships and sexual expression. Some ways you can do this include:

- Providing your office contact information so that they can email or call you directly.
- Work with clients to identify a trusted adult, such as a teacher, who they feel comfortable with.
- Provide accurate resources such as those listed in the *Resources and additional reading* handout in [Appendix A](#).



Opportunities for privacy

As mentioned previously, the physical care requirements for individuals with NMDs can result in a loss of privacy and limit opportunities for sexual expression³⁰. Your clients may be more closely supervised or observed by caregivers and therefore may not have the same opportunities to be spontaneous and private compared to their age-matched peers³¹. Many families use monitors or a similar device in their child's room to monitor them and their needs throughout the day and night.



Limited privacy can impact opportunities for age-appropriate socialization. Lack of privacy can affect a person's perception of their body, and personal boundaries around inappropriate versus appropriate touch³¹. Additionally, over-protective and restrictive parental attitudes can make fulfilling sexual expression difficult for adolescents with NMD³⁰. You can partner with your clients and families to advocate for opportunities for privacy.



How can you support your clients to achieve privacy?

- Advocate for predictable periods of the day where the monitor is turned off to provide consistent privacy.
- Assist your clients to explore call bells and other alerting systems.
- Provide information about accessing attendant care and personal support worker services.
- Encourage use of personal support workers or attendants to assist with set up and clean-up of toys and tools, positioning, and managing clothing before leaving them in privacy for activities related to sexual expression.



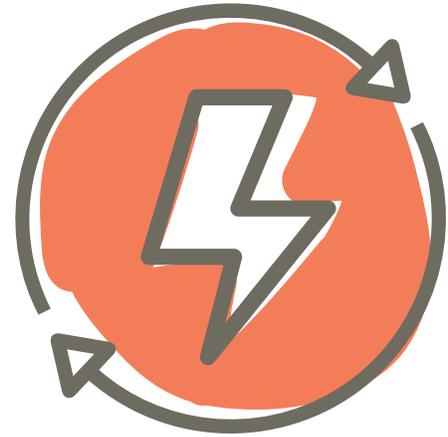
It can be challenging for parents to talk to their children about sexual expression. The [Talking to your child about sex](#) handout can support caregivers with these conversations.

Energy conservation

Increased fatigue is a common symptom of NMDs and is generally chronic³². In some NMDs, acute episodes of worsened fatigue can be brought on by excessive physical activity or physiological distress³².

Sexual activity has been shown to be equivalent to mild to moderate physical activity in young individuals, particularly for those who are assigned male at birth³³. However, these results may not be applicable to all individuals, especially those with a disability³³. Youth with NMDs may exert more energy and have a greater demand on their body during sexual activities.

Energy conservation techniques are an essential part of daily life for your clients with NMDs and there are many resources that describe therapeutic approaches to energy conservation generally^{34, 35}. While many of your clients with these diagnoses will be familiar with energy conservation strategies by the time they are a teenager or young adult, they may require support applying these practices to sexual expression. Specific energy conservation strategies can be explored to help youth with NMDs balance their energy, decrease the impact of fatigue and strain on the body, and ultimately engage in sexual activities in an enjoyable and safe way. This will likely involve considering energy conservation in a greater context as well as within activities related to sexual expression. The commonly used “4 P’s of energy conservation” are applied to sexual expression in descriptions below. While the 4 P’s are described separately below, in practice they are used together based on the individual needs, goals, and lifestyle of each client. Some healthcare professionals have more experience and practice knowledge in this area. If this is not an area of expertise for you, referrals to appropriate providers can be made.

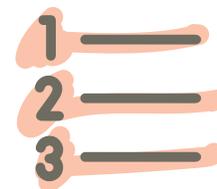


There is a client handout that addresses energy conservation. This may be a useful tool to share with clients as you work on this together.

The 4 P's of energy conservation and sexual expression

1. **Prioritize:** Decide what activities are most important each day

Activities related to sexual expression should be considered within the context of your client's day. If it is important for your client, they may choose to leave another task that is less important to them for another day. How your client prioritizes sexual expression within their day may impact the amount of energy they have for other activities or outings. It is okay for your client to make sexual expression a priority when it comes to energy conservation!



Providers who support energy conservation can work with your client to:

- Determine when they feel fatigue, what precipitates that fatigue, and what strategies they have in place to manage their energy levels.
- Collaborate with your client to prioritize what is most important to them within the context of their day.
- Prioritize preferred sexual activities when they have the most energy.

2. **Plan:** Think about what has to be done ahead of time

Individuals use energy at rest and during physical activity. You can work with your client to identify their meaningful daily activities. By planning, your client can be more mindful of their activity level, build breaks into their schedule, and can try to avoid doing too many activities in one day.



Providers who support energy conservation can work with your client to:

- Provide coaching about how to schedule activities throughout the day and/or week.
- Encourage clients to consider delegating certain tasks to others when possible.
- Encourage clients to schedule time to rest.
- Plan to involve a caregiver in set-up, positioning, or managing clothing.
 - A sexual or romantic partner can also be involved in planning (e.g. timing, location, preparation), or can be part of the plan.
- Engage in advanced preparation to ensure that their day is not filled with extraneous tasks before or immediately after the sexual activity.
 - Gather the equipment they need in advance such as toys, tools, and adaptive devices.
 - Preparation tasks can also cause fatigue so thoughtfulness around planning can also help conserve energy.

3. **Pace:** Taking breaks through the day and during activities

Activity pacing is used to modify activities to help improve overall function and reduce symptoms such as pain and fatigue³⁶. Examples of activity pacing include incorporating breaks in between activities, performing the activity at a comfortable pace, and using [toys and tools](#).

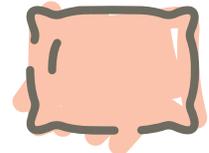


Providers who support energy conservation can work with your client to:

- Encourage scheduling time to rest.
- Consider timing of set-up relative to the activity.
- Adapt the activity so that they can be fully engaged and successful.
- Determine which activities require more effort and energy. Your client can learn to self-assess activities and rate what they perceive is light or heavy sexual activity.
- *Light sexual activities* could include kissing, watching something arousing, reading a romantic novel, fondling, sensory play, and texting or calling their partner(s).
- *Heavy sexual activities* could include masturbation, intercourse, and oral sex.
- Use toys or tools to decrease the effort required during sexual activities.

4. **Positioning:** How your body is set up and supported in space

Strategies on efficient use of the body are an important part of energy conservation education³⁷. As a result of postural weakness, many individuals with NMDs require supportive positioning to optimize their participation and comfort. Positioning recommendations are typically individualized. Clinical presentations of NMDs vary greatly as do personal preferences with respect to sexual expression. Both need to be considered when making recommendations in this area.

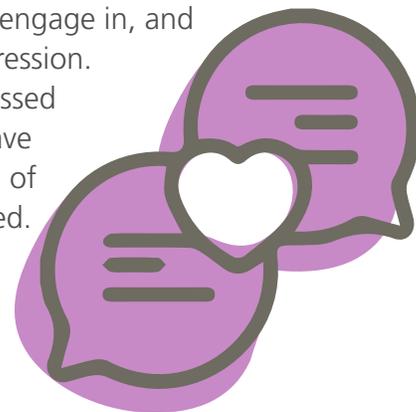


Providers who support energy conservation can work with your client to:

- Explore positions that promote your client's ability to perform desired activities related to sexual expression (see [Supportive positioning](#) handout). Your client's comfort, access to their own body, and access to their partner's body should be considered.
- Complete a physical assessment when addressing specific positioning needs. This can be simulated on a plinth or using a client's wheelchair in a clinical environment. If practice settings allow, assessment can also be completed in the home environment.
- Recommend equipment to support positioning for sexual expression. This might include a hospital-style adjustable bed, pillows, rolls, wedges, or more specialized options (see [Positioning products](#) handout).

Supportive positioning

Occupational therapists and physiotherapists are professionals with expertise in positioning. Biomechanics and task-analysis can be helpful when supporting clients' sexual expression⁵. As described above, your client's abilities, the activities they wish to engage in, and their environment are factors that impact positioning for sexual expression. Positioning is an important part of [energy conservation](#) and is addressed in that section of this guidebook. Not all healthcare professionals have experience and practice knowledge in this area. If this is not an area of expertise for you, referrals to appropriate providers are recommended.



Safety considerations for positioning for sexual activities

- **Transfers:** Consideration should be given to how your client transfers and whether they require assistance to ensure their safety. This may impact decisions about location and timing of activities related to sexual expression in addition to specific positioning recommendations. Since clients with NMDs can fatigue easily, education can be provided regarding the fluctuations in support needs based on energy levels, which may be impacted by sexual activities.
- **Weakened respiratory muscles:** Individuals with NMDs may have weakened respiratory muscles which can result in challenges with breathing³⁸. Therefore, positions that put pressure on a client's chest or diaphragm should be avoided to prevent shortness of breath³⁹. If a client has complex respiratory needs it may be beneficial to consult with their respiratory team to determine what positions are optimal, and whether use of respiratory equipment is required.
- **Impact of position on communication:** Individuals with NMDs may use range of communication strategies. Communication as it relates to sexual expression, including consent, pleasure, and feedback is addressed earlier in this guidebook (see [Consent for sexual expression](#) and [Friendships and relationships](#) sections).



See the client handout [Supportive positioning for sexual expression to provide your clients with practical strategies to consider in conjunction with your assessment](#).

Positions for sexual activities

Below are some suggestions of supportive positions that can be considered for your clients to try with or without a partner. Supportive positioning can facilitate device use by improving reach to genitals⁴⁰ or by allowing toys to be used hands-free⁴¹ (see [Toys and tools for different physical abilities](#) section and relevant client handouts for more information).

Supine

Supine can be a supportive position as your client does not need to work to hold their body in an upright position against gravity. This position may be helpful for youth with NMDs who experience muscle weakness, fatigue, pain, hypotonia, or ataxia⁴². For your clients with NMDs, spinal curvature (scoliosis, lordosis, and kyphosis) as well as contractures and respiratory status can impact comfort in supine. Your client may need accommodations in supine including cushions under their lumbar spine, and/or under their knees to increase support and comfort. Cushions can be used to adjust pelvic position or angles. Placing a cushion under the knees can also improve access to the perineal area⁴³. Supportive positioning may help ease muscle spasms and lower back pain⁴³.



Without modifications, supine may not be a beneficial position for your clients with NMDs who have weakened respiratory muscles. If your client has access to an adjustable bed, raising head of bed or alternatively use of a wedge can help with breathing and secretion management in supine. This position can be used with a partner or without a partner for self-exploration.

Side lying

Side lying can be a supportive position for your clients to engage in self-exploration or partnered sexual expression. Similarly to supine, this position provides support for the body. It also helps bring the hands and arms to midline with decreased effort. Pillows placed in between the knees may increase comfort and support, as well as improving access to their genitals⁴³. Additional pillows or supports behind their back can provide increased stability in this position.



Seated

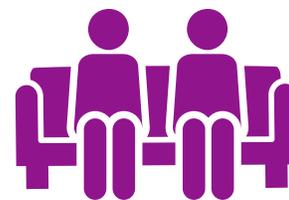
Sitting unsupported can be a challenging position to achieve and maintain for individuals with muscle weakness including teens with NMDs. Supportive seating can provide postural support to maximize participation in sitting and may facilitate clients' access to their body for sexual expression.

Wheelchair: Use of a wheelchair for sexual expression can eliminate the need to transfer. Wheelchairs with power features can allow for increased variety in positioning. Options for positioning can be increased using wheelchairs with removable/swing away armrests, foot supports, and lateral supports⁴⁴. Some power features, like tilt or recline, can be used to decrease the demand on postural muscles and may improve access to parts of the body. Additionally, clients often have access to their devices such as their cell phone or communication device when seated in their wheelchair. These tools may play a role in communication during sexual expression.

If using a manual wheelchair, it is advised to position the chair with the back against a wall to increase safety and/or toy use and stability⁴⁴.



Using furniture: Your client can experiment with a variety of furniture including a couch or a chair⁴⁴ based on the level of postural support they require. An adjustable bed like a home-style hospital bed can provide a variety of positioning options for sexual expression. Adjustability of the head of bed, foot of bed, and height of bed can support positioning and access for both partnered and individual sexual expression.



Using activity of daily living (ADL) equipment: Some of your clients may prefer to engage in sexual activities during daily tasks like bathing. Use of supportive commodes, adaptive tools (see [Toys and tools for sexual expression](#)), and hand-held shower heads can support sexual expression. Sexual expression during bathing can make clean up easier and may fit into existing schedules. An individual can ask for a period of privacy from caregivers during these activities. If engaging in partnered activity, weight capacity of equipment, risk of tipping, slippery floors and other safety factors should be considered.



For more specific suggestions and instructions about sex and disability including detailed positioning descriptions, please see the following resources:

- *The Ultimate Guide to Sex and Disability: for all of us who live with disabilities, chronic pain, and illness* by Miriam Kaufman, Cory Silverberg, & Fran Odette.⁴⁴
- *PleasurAble: Sexual Device Manual for Persons with Disabilities* by Kate Naphtali, Edith MacHattie, Andrei Krassloukov, & Stacy Elliott.⁴³
- *Setting Up for Solo Sex* by Andrew Gurza and Angus Andrews in: *Bang! Masturbation for People of all Genders and Abilities* by Vic Liu.

Positioning products

Based on assessment, healthcare professionals who have practical experience and knowledge in supportive positioning will be able to recommend products including wedges, pillows, and other specialized positioning products to help optimize positioning for sexual expression. There are also products that support with positioning and accommodate toys for sexual expression.



The [Positioning products](#) handout provides information about some specific product options.

Toys and tools for different physical abilities

Clients with NMDs may experience muscle weakness/atrophy and loss of sensation. Patterns of muscle weakness will vary across conditions and individuals. This is an important consideration when making recommendations for toys and tools for sexual exploration. There are many toys and tools with different accessible features. Adaptations can be made to traditional toys and tools to suit your client's abilities. Positions that support posture or enable hands-free use of toys can be recommended (see [Supportive positioning](#) section for more information). We acknowledge that supporting toy and tool selection is not within all HCPs scope of practice. If this is outside of your practice area, support your client by referring them to an appropriate resource. Your understanding of NMDs may be used in collaboration with a sex therapist/counselor or other professionals as appropriate.



Considerations when discussing and recommending toys and tools to assist with sexual expression

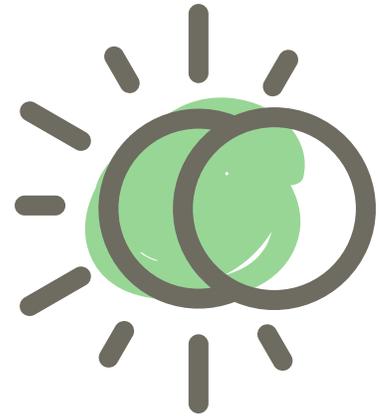
Toy and tool selection can be informed by your clinical knowledge of NMDs, engaging in discussion with clients about their preferences, and whether your client will be engaging in solo or partnered play. There are a variety of toys and tools to support with sexual expression that may be helpful to individuals with NMDs – many are available commercially, and new products are released regularly^{45, 46, 47, 48}. Your client may need to try several options before they find the right fit for them. This section is meant to be used as a guide for HCPs to support their clients with NMDs to make decisions about what might work best for them.



Specific examples of toys and tools as well as some additional considerations can be found in the [Toys and tools for sexual expression](#) handout.

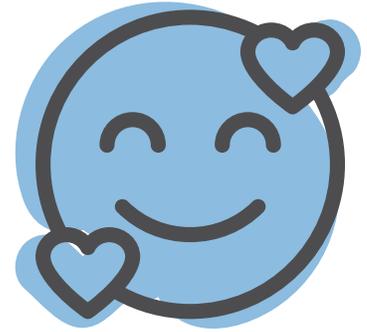
- **Distal weakness and weak grip strength:** Individuals with weaker grip strength may benefit from larger handles, use of universal grips, and consideration of hands-free toys and tools. It is important to consider ease of use including the ability to access buttons to control power or settings. Toys that can be placed on a finger, wrapped around a hand, or used by Bluetooth may be more accessible for individuals who have decreased hand strength⁴⁵.

- **Proximal weakness:** For individuals who have proximal weakness, use of automatic toys or toys with vibration may be preferred. Hand-activated toys that do not require repetitive motion may be more comfortable^{45,47}.
- **Contractures:** Your clients who have limited range of motion due to contractures may benefit from flexible toy options that can be bent or positioned to improve access⁴⁶. Your clients with contractures may also enjoy toys that can be placed or used hands free.
- **Limited active movement/upper extremity function:** Consider toys that can be placed using positioning tools (see [Supportive positioning](#) section), or toys that can be placed in underwear. There are options that can be used to stimulate a penis or vagina^{45, 46, 47}. Many of these toys can be controlled using a cell phone by Bluetooth so the user can control the toy with use of a finger^{45, 48}.



Safe sex practices

Teens and pre-teens typically receive the majority of their sexual health education in school during physical education classes. Students with physical disabilities, such as NMDs, are often excused from, or self-select out of, physical education classes so do not receive sexual health education⁴⁹. As a result, they may not have the same level of knowledge as their same-aged peers regarding sexual health, including safe sex practices. You can encourage your clients to participate in these typically mandatory courses and/or ensure that they are aware of the risks of opting out of sexual health education.



There are many existing resources about contraception and safe sex that your clients can be referred to. However, some methods of contraception are not appropriate for clients with NMDs and may pose a health risk²⁷. You can recommend that your clients talk to their doctor about different methods of contraception and protection from sexually transmitted and blood borne infections (STBBIs). Clients do not need to be sexually active to engage in this education. Steroid-treated individuals with DMD may have additional considerations when selecting contraceptives due to anatomical differences (see [Appendix A](#) for more information).



Your clients may have a lot of questions. The [Questions to ask your doctor client handout](#) can be a helpful guide to start these conversations.



The [Duchenne Muscular Dystrophy, steroid treatment, and puberty client handout](#) has information about steroid treatment and its impact on puberty.

Conclusion

While we know this guidebook could be several chapters longer, our hope is that the information we have chosen to include serves as a springboard in your learning around sexual expression as it relates to individuals with neuromuscular conditions. You are encouraged to explore the resources within this book, including the client handouts, and to find your own great resources in the areas and locations where you provide care.

Thank you for taking the time to take in this information, working to eliminate stigma around sex and disability, and supporting your clients with NMDs to participate and enjoy these meaningful activities!



APPENDIX A:

Specific considerations for neuromuscular conditions

Individuals with neuromuscular conditions commonly present with muscle weakness, decreased endurance, and contractures. There are considerations for these common characteristics throughout this guidebook. Different conditions may present with different patterns of weakness, so it is important to educate yourself about the conditions your clients present with.

The following are additional specific considerations associated with neuromuscular conditions; much like other disabilities, they present on a spectrum. This section is intended to highlight key considerations that might impact sexual expression for various conditions, but is not an exhaustive list. As always, it is essential to complete the necessary assessments with your clients to understand their strengths and needs to best support them to achieve meaningful participation.



Rhabdomyolysis

Individuals with muscle conditions are at an increased risk for rhabdomyolysis, or muscle breakdown caused by overexertion. Rhabdomyolysis occurs when myoglobin gets released, due to the breakdown of muscle fibers, into the bloodstream⁵⁰. Serious complications can occur such as kidney failure. The common signs of rhabdomyolysis are muscle pain in the shoulders, thighs, or lower back, increased muscle weakness, and dark red or brown urine⁵⁰. Since sexual activity is considered physical activity, health care professionals should educate their clients about seeking medical attention immediately if they notice any signs of rhabdomyolysis. If a client experiences rhabdomyolysis they must go to the emergency room to seek urgent medical attention. If clients have questions about this or are not sure if they are at risk, they should speak to their neuromuscular doctor.

Use of ventilation or BiPAP

Individuals with NMDs may require respiratory support including use of ventilators, BiPAP, etc. For some individuals with NMDs, this is required for specific periods of time (for example, while sleeping), for other individuals it is required at all times. Since sexual activity is considered physical activity, if a client uses respiratory support, consultation with their respiratory team may be of benefit to determine if extra support is required during or after sexual activity.

Duchenne muscular dystrophy (DMD) and steroid treatment

Steroid treatment can affect the timing and rate of puberty changes^{51,52}. Individuals treated with steroids are more likely to start puberty late (delayed puberty). The dose of steroid as well as the age steroid treatment is started may affect when a client starts puberty.

Individuals experiencing delayed puberty may be shorter in stature than their peers, have little or no facial, body, or pubic hair, have a smaller penis, and have a higher voice⁵². If your steroid treated clients with DMD have questions about delayed puberty, or are interested in exploring treatment options for this, they should be directed to their neuromuscular doctor.

Individuals with DMD who are treated with steroids typically have a smaller penis size⁵³. This may impact what sexual activities look like for them, which toys and tools work for them, and use of contraceptives. There are many considerations for adaptive toys and tools within this guidebook.

External condoms with a tighter fit are recommended to protect against sexually transmitted infections and unwanted pregnancy. Tighter fitting or custom made external condoms are available for clients who need them based on their anatomy. Some examples include:

- **Iron Grip Condoms by Caution Wear Condoms:** These condoms have a snugger fit and a smaller width, designed for individuals who have trouble with condoms falling off⁵⁴.
- **LifeStyles Snugger Fit Condom:** These condoms have a tighter fit on the shaft to prevent them from slipping off⁵⁵.
- **My One Condom:** Custom condoms, individual measurements are completed and submitted for each order⁵⁶. These can be found at: <https://www.myonecondoms.com>



There is a client handout with additional information about DMD, steroid treatment, and puberty.

Weakening of facial muscles impacting facial expression

Facial muscles are impacted in some neuromuscular conditions. Examples of conditions where facial muscles are impacted include: Facioscapulohumeral muscular dystrophy (FSHD), Nemaline rod/body disease, congenital myasthenic syndromes, congenital myotonic dystrophy, and congenital myopathies. For individuals who have decreased ability to communicate through facial expressions, other forms of explicit communication are essential for building and maintaining relationships, communicating needs and wants, and sharing feelings⁵⁷. Individuals with these conditions may benefit from specific interventions related to communication strategies. A team-based approach including social work, psychology and speech language pathology, with a focus on coaching, is recommended from an early age to help individuals develop skills in these areas.

The weakening of facial muscles will also impact tongue movement and saliva control.



Unclear or inaudible speech

Some individuals who have NMD may have unclear speech and/or decreased volume, making their speech difficult to hear. Alternative communication strategies and considerations can be found throughout the guidebook, including in sections related to [Consent for sexual expression](#) and [Supportive positioning for sexual expression](#).



Decreased sensation

Individuals with NMDs including Charcot Marie Tooth (CMT) and other neuropathies may present with decreased sensation⁵⁸. Typically, this is found distally impacting the hands, feet, and lower legs. Due to decreased sensation, individuals with these conditions must take extra precautions to protect these body parts from injury (due to extreme temperature, chafing, impact, etc.). Due to decreased sensation, it is recommended that individuals with these conditions test temperature, level of vibration, etc. with a more proximal part of their body to determine an appropriate setting.

Hearing loss

Hearing loss can be present in some NMDs, for example FSHD and CMT^{57, 59}. Considerations for reciprocal communication as well as environmental awareness and privacy should be considered. If your client presents with hearing loss, it is recommended that they have a team of specialists including audiology and speech-language pathology involved from an early age to support with communication and environmental strategies.

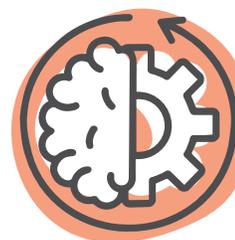


Skin integrity

To prevent skin breakdown, clients with NMDs should be cautious around activities that may cause skin friction, or that require prolonged positioning. If your client has active skin irritation/breakdown and/or pressure injury, positions and activities that prevent further damage should be considered⁴³.

Cognition and learning

Some individuals with NMDs may also have diagnoses related to their cognition and learning. This could be a completely separate diagnosis or associated with their NMD. Your clients with intellectual or learning disabilities may require modifications to how the sexual expression and health information and education is delivered. There are many resources about talking to individuals who have intellectual disabilities including ones with visual aids (see the [Resources and additional reading](#) handout or [Appendix B](#)). Learning disabilities are common in some NMDs. Understanding the learning profile and strengths of a client can be helpful when presenting new and complex information, including that related to sexual health and expression. If a psychological assessment has been completed it can assist you in tailoring your education and approach.



Ataxia

It was challenging to find reliable information about the impact of ataxia on sexual expression. However, given that it is a condition that impacts controlled movement, considerations for ataxia should be taken into account for use of toys and tools, positioning, facial expression and tongue movement, and other areas of sexual expression. There is evidence that 83% of individuals with Friedreich's Ataxia (FA) reported some symptoms impacting sexual function⁶⁰. There are also reports of erectile dysfunction in FA⁶¹. Clients who report concerns in this area can be directed to their medical team.

Other considerations related to NMD

There is limited information about considerations related specifically to sexual function for individuals with NMDs. If your client has any questions about their body, sexual functioning, or side effects of medication, they should contact their doctor. In addition to FA, there have been some reports of erectile dysfunction in men with myotonic dystrophy⁶². In Spinal muscular atrophy (SMA) there is a report that indicates individuals may experience vaginal dryness as a side effect of medication⁶³. Risdiplam may impact a male's fertility⁶⁴. Medications can also impact pregnancy. If your client takes medications for their NMD and are family planning or become pregnant, they should inform their medical team immediately.



Appendix B:

Resources for clinicians

These resources are being provided in addition to the comprehensive list that is included as a client handout, “Resources and additional reading” in [Appendix C](#). Some of the resources included here are specifically directed at clinicians and are not in the client handout while others can be found in both. You are encouraged to explore resources to further develop your knowledge when supporting clients who have goals related to sexual expression.

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/>

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

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

Clinical practice guideline on roles and interventions in physiotherapy to promote sexuality in adults with a neuromuscular disease. Savoires Udes Depot Institutionnel.

Fisette-Paulhus, et al.

<https://savoires.usherbrooke.ca/handle/11143/19131>

Common issues with physical disabilities and sexuality. Southport and Ormskirk Hospital. A tip sheet listing common issues, as well as considerations for providing sexuality education.

<http://www.southportandormskirk.nhs.uk/wp-content/uploads/2019/03/Common-issues-.pdf>

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

Genderbread Person. Killermann, S. An infographic to support education on the multitudes of gender.

<https://www.genderbread.org/wp-content/uploads/2017/02/Breaking-through-the-Binary-by-Sam-Killermann.pdf>

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=65

http://www.vch.ca/Locations-Services/result?res_id=871

LGBTQ2S+ Terms to Know. Toronto Pflag.

<https://www.torontopflag.org/lgbtq2s-terms-to-know>.



LGBTQ2+ Inclusiveness Toolkit for Inclusive Municipalities in Canada and Beyond. Canadian Commission for UNESCO. (2019).
<https://en.ccunesco.ca/-/media/Files/Unesco/Resources/2019/06/CIMToolkitLGBTQ2PlusInclusiveness.pdf>

Rainbow Health Ontario. Their shop has brochures, posters, and guidelines to support LGBTQ2+.
<https://www.rainbowhealthontario.ca/lgbt2sq-health/rho-shop/>

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/>

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

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

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<https://www.aboutkidshealth.ca/yourteen>

“The Ultimate Guide to Sex and Disability” by Miriam Kaufman, Cory Silverberg, and Fran Odette.



APPENDIX C:

Client and caregiver handouts

These handouts provide general information and a starting point for conversations with your clients. It is highly recommended that these resources are provided in conjunction with a thoughtful assessment and treatment plan. As with any handouts or resources, your clinical judgement will determine which and how many handouts you provide at a time. It is strongly recommended that the *Consent and relationships* handout be provided to all clients either as a starting point, or in conjunction with any other handouts as it provides necessary and foundational information.

You will find the following handouts in this section:

- Friendships relationships and dating
- Consent and relationships
- Energy conservation and sexual expression
- Supportive positioning for sexual expression
- Positioning products
- Toys and tools for sexual expression
- Sexual expression and staying safe
- Questions to ask a doctor
- DMD, steroids, and puberty
- Talking about sex with your child/teen



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
- 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>
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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

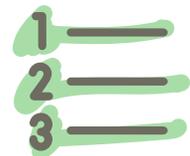
Take breaks or slow down



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.

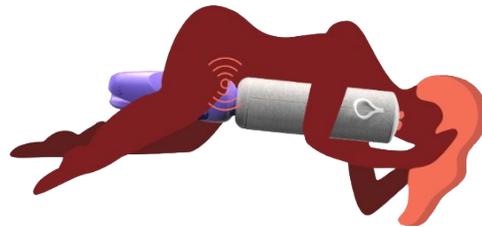
Image reference: http://www.goodvibes.com/display_product.jhtml?id=17BF18&kbid=42691



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



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: https://www.we-vibe.com/ca-en/moxie-plus?gclid=Cj0KCQjwldKmBhCCARIsAP-0rfyvYSd-XgKhpLReWywO6P0_9HT-s-I5bEzeJ062V8xpoCHkXPPoPE8aAjdEALw_wcB | ● | ● | ● | | ● | ● | ● | ● | |

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: https://fleshlight.zendesk.com/hc/en-us/articles/360014581053-Fleshlight-Flight | ● | | ● | | ● | ● | | | |
| 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: https://www.amazon.co.uk/Lovehoney-Masturbator-Black-Blowmotion-Rechargeable/dp/B08P7VJQZJ | ● | | ● | | ● | ● | ● | | |
| Worn on finger | | Fin vibrator – finger vibrator  Image reference: https://mysecretluxury.com/luxury-vibrators/clitoral-and-external-vibrators/fin-by-dame-finger-vibrator | ● | | ● | | ● | ● | ● | | |

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: https://www.delicto.com/en-ca/products/picobong-transformer-vibrator</p> | ● | | ● | ● | ● | ● | | | |
| Pressure control | Squeeze to operate – *degree of pressure required varies by device. | <p>Egg Massager Passion Set</p>  <p>Image reference: https://www.dallasnovelty.com/shop/disabled-sex-toys/sola-egg-passion-intelligent-4-in-1-pressure-sensitive-rechargeable-massager-set/</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: https://joyviva.ca/products/we-vibe-rave</p> | ● ¹ | ● ² | ● | ● | ● | ● | | ● | |

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: http://www.amazon.co.uk/Doxy-Massager-Plug-Vibrating-Black/dp/B00N8TC3CS | ● ¹ | ● ² | ● | | ● | ● | | | |
| Tongue | There is an optional ear piece to help secure in place. | Tongue Star Pleasure Tongue Vibrator  Image reference https://www.amazon.com/Tongue-Pleasure-Star-Vibe-Oral/dp/B086GYRHZB | | ● | ● | | | ● | ● | | ● |

| 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: https://www.comeasyouare.com/products/unicorn-collaborators-thigh-harness | | ● | ● | ● | | ● | ● | | |

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.

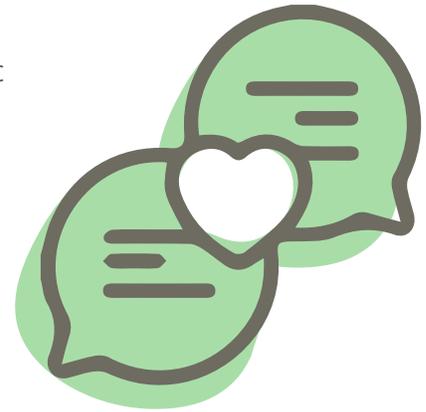
Gender and sexual orientation

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.

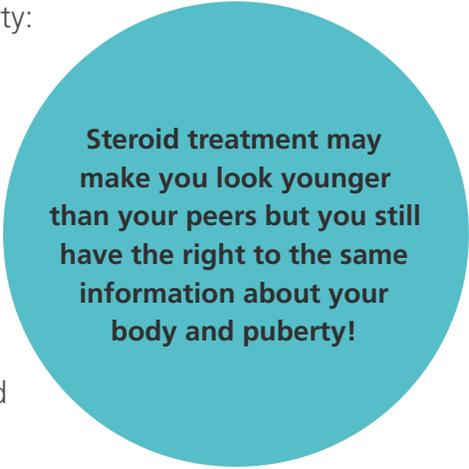
Duchenne Muscular Dystrophy, steroid treatment, and puberty

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?

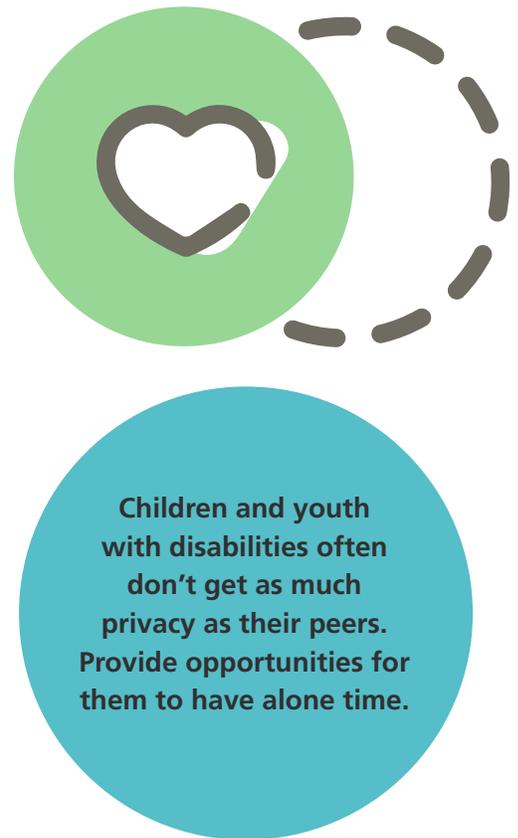
- Talk to your parents and your neuromuscular or family doctor.
- If there are no signs of puberty by the time you are 14 years old you can be referred to a doctor called an endocrinologist. This is a type of doctor that looks after puberty and bone health.
- An endocrinologist might prescribe testosterone, 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

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/](https://www.youtube.com/watch?v=mGX4xaoHt34&list=PLAk6GQXoqtAQjUOoj07Hpr0Qz0NG5spGH&index=4)

[watch?v=mGX4xaoHt34&list=PLAk6GQXoqtAQjUOoj07Hpr0Qz0NG5spGH&index=4](https://www.youtube.com/watch?v=mGX4xaoHt34&list=PLAk6GQXoqtAQjUOoj07Hpr0Qz0NG5spGH&index=4)

(2) women's health

[https://www.youtube.com/](https://www.youtube.com/watch?v=WZTIWMwTO98&list=PLAk6GQXoqtAQjUOoj07Hpr0Qz0NG5spGH&index=6)

[watch?v=WZTIWMwTO98&list=PLAk6GQXoqtAQjUOoj07Hpr0Qz0NG5spGH&index=6](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

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

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

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.extendfamily.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

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

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

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

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>

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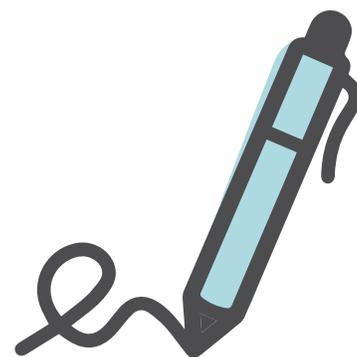


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