

Let's Talk About Sex: A Resource for Parents



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About Us

Muscular Dystrophy Canada is a national not-for-profit organization whose mission is to enhance the lives of those affected with neuromuscular disorders by continually working to provide ongoing support and resources while relentlessly searching for a cure through well funded research. We offer information, education, support, equipment funding and advocacy. For more information about our programs and services, visit our website www.muscle.ca or contact the office nearest you (see back cover for listing).

Introduction

Time has flown by and you realize that your child has become an adolescent who is experiencing the stirrings of sexuality. You would like to give him or her proper guidance, but don't quite know how? *Let's Talk about Sex: A Resource for Parents* was created to support you, the parent of an adolescent with a neuromuscular disorder, during a crucial developmental stage in your child's life.

This guide contains information and strategies on how to approach teenage sexuality - a subject that leaves many parents feeling uneasy. It covers topics like: your role as a parent, puberty, body image and sexual identity, romantic relationships, sex and birth control, and sexual abuse. At the end of each section, you will find further 'avenues for reflection' to help you think things through. And at the end of the guide, a **Resources** section provides references for further information.

Please keep in mind, however, that what we are proposing here is not a "one size fits all" formula that can be applied in all cases. Every situation is unique, depending on the many factors at play, for example, the particular values that a family espouses. These issues are generally sensitive in nature and it's up to you to determine how you will use this information. We believe it's better to provide as much knowledge as possible on these subjects so as to help you and your child make wise and informed decisions.

Although your child may have a neuromuscular disorder, they are not defined by their disability. Your teen may require more care and attention than others but he or she is no different than anyone else at this stage of life in terms of seeking greater autonomy and personal space. While your child's muscles may be weak, **their spirit is strong!**

Disclaimer:

Muscular Dystrophy Canada will not be held responsible for misuse of information or any damages incurred as a result of its use. This resource is not meant to replace consultations with your doctor or to provide medical advice or treatment. For information specific to the condition affecting you or your family, please consult a physician.

Your Role as a Parent

First of all, please be assured that talking with your teen about sex will not lead to promiscuity. On the contrary, your teen already knows more about the subject than you think. Discussing with them will give you an idea of what your child already knows and what he or she thinks about the subject. Don't be surprised if "eyes roll" when you bring up the topic – children are often as much, if not more, uncomfortable than adults discussing sex. But you can be sure this is a subject of interest, and that they will be equally curious about your perspective.

This section will help you determine what role you wish to play in this stage of your child's life, what messages you want to convey with regard to sexuality, and how to deal with any limits you may have on the matter.



How do you begin?

As a parent, you've already been involved in your teen's sexual development. This involvement started at a very young age when you told your child about the differences between men and women or when you started showing them different parts of the human body. Depending on the age and development of your child, this discussion gradually moves to more complex issues like birth control, sexual identity and sexual relations.

However, many parents are nervous about approaching the subject of sexuality with their teenager, and having a teenager with a neuromuscular disorder may create additional questions. Remember that before being a teen with a neuromuscular disorder, your child is a teenager with the same sexual curiosity as any other teen. Of course, certain factors must be taken into consideration, but know that in general, the questions your teen is asking are the same as those all other teens who are not affected with a neuromuscular disease.

Before starting up a discussion with your teenager, ask yourself what is the best way of approaching the subject. Certain attitudes are more conducive to sharing. For example, be available for your child, do not wait too long before addressing the subject, encourage discussion after seeing a movie or a commercial on a particular aspect of sexuality, or educate yourself so you're not taken off-guard during a discussion.

Messages to be conveyed and underlying values

Before beginning a discussion on a topic involving sexuality, take stock of your own values on the subject. Ask yourself if you want your teen to share those values. Our opinions on a particular subject are often based on our past experiences, so we may need to qualify our words. When you want to convey a message to your teen, *how* you say it can be as important as what you say. Here are a few tips:

- Use accurate terms when talking about a body part or bodily function;
- Answer questions as honestly as you can;
- Don't force your point of view on your child, but rather let the discussion be a

mutual exchange;

- Don't expect this to be a one-time-only discussion, or to be done within an hour.

If you keep these tips in mind and each of you feels respected, there's a good chance the communication between you and your teen will go well and will lead to other healthy conversations.

Know your limits

Be aware of your own limitations. If certain topics make you uncomfortable, it's OK to ask a health professional or other responsible adult to talk with your teen. This should be someone you trust and with whom your teen feels at ease, so he or she won't be embarrassed to discuss more intimate issues. At some schools and treatment centres, teens can speak to a nurse, a psychologist or other competent professional about sex-related issues. Enquire with the institution's coordinator.

Puberty

Puberty is a critical stage in your child's development. Your teen's body is maturing. However, depending on the type of neuromuscular disorder, this physical turning point may occur later for your child than for others of the same age. For example, boys with Duchenne muscular dystrophy often have plump, hairless faces, making them look younger than their peers. It is important to keep in mind that despite her or his physical disability, your child is becoming an adult, a sexual being capable of reproduction.

The hormonal development that comes with puberty happens to all adolescents. These changes inevitably lead to an exploration of one's own body and the accompanying sensations, including masturbation. This can sometimes be more complicated for young people with neuromuscular disorders because of a lack of coordination, spasms, pain or muscle weakness. If you are comfortable discussing this very intimate subject with your teen, you should know that there are technical aids, such as body harnesses, that can facilitate this self-exploration. For more information, visit the *Come As You Are* website (Sex and Disability section) mentioned in the Resources section at the end of this document – or contact your occupational therapist.

Avenues for reflection:

1. How do I feel about the changes that are taking place in my child's body?
2. Am I comfortable talking about these changes with my teen?
3. My adolescent is becoming an adult. What thoughts are going through my mind?

Body Image and Sexual Identity

Adolescence is a period of significant change for a child. He or she has to adapt to a new body image, so there are bound to be conflicting emotions. A teenager will also seek greater independence during this time, so they will try to find the right balance between their desire to do things on their own and their parents' authority. This natural evolution may sometimes happen more slowly for a child with a physical disability, because they need help to carry out certain tasks. Nevertheless, you should encourage your teen to take on more responsibilities, let them make more decisions on their own and give them more privacy.

Self-image and the media

Teenagers often compare themselves to others while at the same time wanting to stand out. Since children affected with a neuromuscular disorder have significant physical differences, they may struggle to find ways to make themselves more attractive to others. Like all teens, they must learn to accept their new body image as well as the differences related to their disability. The enormous pressure exerted by media-driven images of beauty can create inferiority complexes, so it's important to talk with your teen about issues surrounding appearance and how comfortable they are in their "own skin."

Stereotypes and their negative influence on body image

When someone does not match the typical stereotypes of beauty, they run the risk of developing low self-esteem, eating disorders and even depression. These stereotypes are often reinforced by media advertising, movies and even fairytales heard at a very young age. You should make your child aware of the dangers of such stereotypes and make it clear that only a very small percentage of people actually meet these media-driven standards of beauty. You could look at some images together and encourage your teen to develop a critical view of advertising, or watch the videos on the Dove website. This way, your child will be better equipped to face stereotypes.

As mentioned before, low self-esteem can have very negative consequences, such as eating disorders. Anorexia and bulimia are mental illnesses that endanger the lives of those affected by them. It is important to see a health professional if you notice that your teen has an unhealthy relationship to food.

Avenues for reflection:

1. What is my own body image?
2. How does this perception affect my teenager?
3. What body image do I have of my child?
4. What messages am I sending to my teen about his/her appearance?
5. What are the physical attributes of my teen that others may find attractive?
6. Knowing the difference between learned self-image and the unchangeable, unique and innate "Real Me."

Sexual orientation

The teenage years are an important time of self-discovery, so your teen may question his or her sexual orientation. He or she might be attracted to people of the same sex (homosexuality) or to people of both sexes (bisexuality). This often leads to great inner turmoil in teens and a great fear of rejection by their peers.

When discussing sexuality, the golden rule to follow is to be open-minded and accepting. It is important that your teen know that there's nothing abnormal about being homosexual or bisexual. You can show them that you are open-minded on that subject and that they can come to you if they have questions. If you are not comfortable discussing the subject, you could direct your teen to a trusted person he or she can turn to if needed.

Avenues for reflection:

1. How would I feel if my child were a homosexual or a bisexual?
2. How do I feel about homosexuality and bisexuality?
3. What messages and values do I convey about homosexuality and bisexuality?

Romantic Relationships

It is typically during adolescence that we develop our first romantic feelings for another person. It's a time when a young person wants to be loved and appreciated by someone other than their parents. This can be tricky ground for the parent, but try not to be overly possessive since that may backfire. Another issue that can arise is that you may fear your teen will be rejected or hurt by the person to whom he or she is attracted. So ask yourself this question: "If my child didn't have a physical disability, would I be so opposed to him or her having a romantic relationship?" If the answer is No, you may need to work on yourself so as not to hinder your teen's personal development.

Keys to a successful romantic relationship

In a romantic relationship, as in life in general, it takes work to succeed. It might be good to talk with your teen about the keys to achieving harmony in a relationship. The concepts presented here should not be considered the only good solutions – think of them rather as avenues for discussion. First of all, there is **respect for oneself and for the other person**; this means awareness of one's own limits and those of the partner in trying to find mutually satisfying compromises. Another factor in the search for harmony is **trust in the other person**. For instance, if one constantly questions the other about their comings and goings, it can create a feeling of suffocation after a while. It's also important to try and avoid jealousy in order to build and maintain a strong relationship. A person with jealousy issues may need to work on themselves or seek counselling in order to be less controlling.

Here is another important point to bring up with your teen: his or her romantic partner is not a replacement for you. If they are looking for someone who can provide the same care and attention that you do, there is a real risk the relationship will go awry. In love, one should desire the other person without always expecting to be taken care of as in a nurse/patient relationship. Talk to your teen about her or his expectations in a romantic relationship and the role of each partner.

What does love mean to me and my child?

As an adult, you have had more experience in interpersonal relationships, whether directly or indirectly. Each of these relationships has served to shape your ideas about love. Before approaching the subject with your teen, take time to assess your own feelings and to think about what you want to tell your child about romantic love. Your child may not think the same way as you do, but don't impose your ideas on them, otherwise they may hold back from discussing the subject with you again in the future.

Avenues for reflection:

1. What are my feelings about love?
2. What messages do I want to pass on to my child about love?
3. How do I feel about my teen getting involved in a romantic relationship?

Online Dating

Internet dating is becoming increasingly popular in all age groups, and it might be an attractive option for someone with mobility problems. It is therefore very important that your teen be warned about the potential dangers of online encounters.

If your teen is interesting in online dating, you may want to set some limits, such as:

- Do not share any personal information (telephone, address, school, etc.).
- Do not send naked or explicit photographs of or undress for someone online
- If your online relationship is going well, and you want to arrange an in-person date, someone you trust should accompany your teen and the meeting should be in a public space (not in someones home).

For futher reading on this topic, visit:

<http://www.onlinedatingmagazine.com/features/onlinedatingsafetytips.html>

<http://www.onlinedatingsafetytips.com/>

<http://www.getsafeonline.org/social-networking/online-dating/>

Sex and Birth Control

Before bringing up the subject of sex with your teen, think about the messages you want to convey about sexuality in general and more specifically about his or her sexuality. Sex can take place without penetration, for instance, petting, body kissing or mutual masturbation, all of which are part of sexual relations. You may suggest to your teen that when two people are having sexual relations, “performance” should not be a concern. In physical intimacy, tenderness and affection are important to normal human development.

There are various birth control methods that reduce the risk of unwanted pregnancy and are effective when used properly. Some also protect against sexually-transmitted and blood-borne diseases. However, some of these methods are not appropriate for a teenager with a neuromuscular disorder. In fact, some are contraindicated as they may pose a health risk, so you should talk to your doctor about the different methods of contraception.

The birth control pill, the patch and vaginal rings: These methods prevent ovulation, thereby reducing the risk of fertilization and pregnancy. However, they are **not** recommended for your daughter with a neuromuscular disorder because they may increase the risk of blood clots.

Depo-Provera: This is an injection given four times per year. It is likely to stop menstrual cycles after the first year of use, so it’s practical in terms of hygiene. It also contains no estrogen, a hormone that can cause blood clots. On the other hand, it’s important to note that this treatment may reduce bone density, so your doctor might recommend a calcium supplement. When injections stop, Depo-Provera may remain active for another nine months and continue to prevent fertilization.

The IUD (coil): This method is available in two forms, with or without hormones. Like Depo-Provera, the intra-uterine device with hormones contains only progesterone and may therefore be a good option. Whichever form is chosen, it works for five years. One drawback is that it must be checked regularly to ensure the two “arms” of the device are staying in place. Furthermore, bleeding may occur between menstrual periods in the first months after implantation by the doctor.

The diaphragm: This method requires a significant amount of manipulation. A doctor’s advice is needed to determine the correct size. When properly used, it creates a sperm barrier. For greater effectiveness, a spermicide should also be used.

Condoms: This is the only contraceptive available for males. Condoms vary greatly in size, texture, colour, etc. Most are made of latex, but people who are allergic to latex can choose polyurethane condoms. This method protects against some sexually-transmitted and blood-borne infections (STBBIs). Please note that if a lubricant is used with a condom, it must be water-based.

The female condom: This method offers the same advantages as the male condom: it's very effective against STBIs and unwanted pregnancies. A gel lubricant is recommended for added comfort. However, installing the female condom can be challenging and a few tries may be necessary. The female condom is also more expensive than its male counterpart.

Reminder: only the male and female condoms provide effective protection against some sexually-transmitted and blood-borne diseases. The other methods only reduce the risk of unwanted pregnancy.

Avenues for reflection:

1. Do I feel comfortable discussing birth control with my teen?
2. What, in my opinion, constitutes sexual relations?
3. What are my views on sexuality?

Sexual Assault and Abuse

People with physical disabilities are more vulnerable to sexual abuse because they receive personal care from many attendants, some of whom may be inclined to take advantage of the situation. The abuse can also be perpetrated by a member of the family.

Encourage your child to confide in you regarding any uncomfortable situation, including if someone hurts or touches them in a way that causes distress or makes them feel ill at ease.

You could approach the subject by asking your child if he/she knows the difference between appropriate and inappropriate touching. You can explain that there are different forms of sexual abuse, including offensive words, inappropriate touching made to appear accidental, sexual solicitation. Empower your child to be assertive and speak out (say NO) against any form of inappropriate intimate contact.

Common signs of abuse include sudden outbursts of aggression, hypersexuality (increased sexual urges) or hyposexuality (complete loss of sexual interest). If you notice any of these behaviours, let your child know that you are there to listen without judgement and provide support. Become informed about resources that are available in your community, such as a sexual assault center or hotline, counseling services, or social worker assistance.

Concluding Remarks

Just like every young person, your teen is at an important stage of development: adolescence. Despite dealing with a neuromuscular disorder, he or she is experiencing the same physical and psychological changes that come naturally at this age – becoming a sexual human being capable of reproduction. See this time as a wonderful opportunity to connect with your child in new ways. Know that there are certain attitudes which will facilitate these discussions. Above all, each of you must feel respected. For your teenaged girl, it's the time to talk about periods, preferably before they begin. There are other important issues to consider, like the importance of personal hygiene and the new physical sensations your child is experiencing.

You may also take this opportunity to help your teen develop a new self-image. Don't forget to warn them about the dangers of sexual stereotypes that pervade the media. You will also notice a greater need for independence and privacy that's normal for this age. When it comes to romantic relationships and sex, think about the messages you want to pass on to your teen – while trying not to impose your own views about things. As for birth control options, it's always preferable to consult your doctor. Finally, you can play a role in protecting your teen against sexual abuse. Be sure they know their rights and, if need be, remind them that they can talk to someone they trust.

Resources

Websites

Dove

This site features videos that promote the natural beauty of all people. These clips may be a good way to start a discussion about body image. www.dove.ca

Sexuality and U

This site deals with topics like male and female anatomy, contraception and STBBIs; it also gives parents tips on how to approach the subject of sexuality with their teens. <http://www.sexualityandu.ca/>

Come As You Are

This site addresses themes related to sexuality and includes a section for the physically disabled. There is also information on various sexual aids. <http://www.comeasyouare.com/>

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Muscular Dystrophy Canada's mission is to enhance the lives of those affected with neuromuscular disorders by continually working to provide ongoing support and resources while relentlessly searching for a cure through well funded research.