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Sex and neuromuscular conditions

Being sexually active is a part of normal life. A diagnosis with a neuromuscular condition doesn't mean that this part is over. Read below about the 5 common myths associated with sex and disability. For help with your sexual and reproductive health Family Planning is a great resource. They can offer you health information, clinical services, education, training and research and work with people of any gender, age, ethnicity or sexual orientation.

Sex and Sexuality

You're talking about it, reading about it, and watching it wherever you go. But a lot of what you read, see, and hear about sex and sexuality is inaccurate, confusing, or even harmful. A basic understanding of sex and sexuality can help you sort out myth from fact and help you make good decisions about your sexual health.

Our sexuality affects who we are and how we express ourselves. There's a wide range of how people experience their sexuality. Some people are very sexual, while others experience no feelings of sexual attraction at all. Your sexuality may be influenced by your family, culture, religion, media, friends, and experiences. No matter how important sexuality is to you, we all have thoughts, desires, attractions, and values that are unique.

Sexuality is about much more than just sex. It includes your body, including your

- sexual and reproductive anatomy and body image
  - how you feel about your body
    your biological sex - male, female, or intersex
    gender - being a girl, boy, woman, man, or transgender , or genderqueer
- your gender identity
  - feelings about and how you express your gender
- your sexual orientation
  - who you're sexually and/or romantically attracted to, your desires, thoughts, fantasies, and sexual preferences
- your values, attitudes, and ideals about life, love, and sexual relationships
- sexual behaviors- including masturbation

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It's normal to have questions about sex and sexuality. And the good news is the more you know about it, the better you'll be able to take charge of your sexual health.

For more information visit http://www.plannedparenthood.org/health-topics/sexuality-4323.htm

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Body Image and Sexual Health

Body image is an important part of your sexual health. People who feel comfortable in their bodies are more likely than others to make healthy sexual decisions, like protecting their health by using condoms. People who feel comfortable with their sex organs are more likely to be comfortable talking openly about sex with a partner. People who feel ashamed of their bodies, including their sex organs, may not feel confident and strong enough to make healthy sexual decisions.

What Is Body Image?

Body image is how you feel and what you think when you look at yourself. It's also how you imagine other people see you.

How you feel about your body and all of its parts - your build and your legs, nose, stomach, the color of your skin, and the color or texture of your hair, for example - plays a role in your body image. This also includes your sex organs - the vagina and vulva, breasts, or penis.

What Can I Do to Improve My Body Image?

There is a lot you can do to improve your body image, even without changing your body. Remember, body image is not about how you look, but how you feel about the way you look.

Some people choose to change the way they feel about their bodies. Many times, talking with a person you trust, such as a friend or family member, about the way you feel can help. Professional help from a therapist may also be useful. Talking about your negative feelings and developing new ways to think about your body and your self-worth is a good way to address a negative body image.

Think differently about your body. Pay attention to the times when you feel bad about your body. Did you just weigh yourself? Did you just read a magazine? Did you just talk to a friend or family member who is negative about her or his body?

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Tips for a Positive Body Image

In a world that is constantly showing you narrow definitions of beauty, how can you maintain a healthy body image? Here are some tips:

- Remember that health and appearance are two different things.
- Accept and value your genes - you probably inherited a lot of traits from your family members, so love those traits as you love your family.
- Keep a list of your positive qualities that have nothing to do with your appearance.
- Surround yourself with people who are supportive and who make you feel good about yourself.
- Treat your body with respect and kindness.

People may choose to change their appearance in many ways, for a variety of reasons. If you want to change the way you look, be sure to have realistic expectations. If you have a negative body image, it is important to deal with the mental and emotional aspects of it in order for any physical changes to be truly successful.

Some people choose to make lifestyle changes, such as adopting a specific diet and an exercise program, or change their bodies in other ways. Often, this can be a healthy choice. If you are planning to make a considerable change in your lifestyle, it can be a good idea to talk with a health care provider who can advise you about the healthiest way to do so.

People also change their looks in other ways, such as coloring or processing their hair, or using products to change the appearance of their skin. Some changes can boost your self-esteem and body image, and some changes may not be as effective. The key is to have realistic expectations about how much changing your appearance can change how you feel about yourself.

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FIVE COMMON MYTHS ABOUT SEX AND NEUROMUSCULAR CONDITIONS

Myth Number One
People with disabilities -- especially if they need a wheelchair -- can't feel anything "down there" and can't have a sex life.

THERE ARE MANY KINDS OF DISABILITIES AND REASONS FOR WHEELCHAIR USE. A FEW DISABILITIES CAUSE SOME SEXUAL PROBLEMS; FEWER STILL CAUSE TOTAL DISRUPTION OF SEXUAL FUNCTION.

However, you may be surprised and dismayed to find out how many people actually believe this myth. Even parents of young people with disabilities are sometimes confused about how the disability affects or doesn't affect sexual function.

Some of the confusion may have come about because of heightened attention to spinal cord injuries in movies such as "Born on the Fourth of July" (1989), and widespread publicity about the effects of multiple sclerosis. Both these conditions differ from the neuromuscular conditions that the Muscular Dystrophy Association of New Zealand supports. They both can affect several aspects of the nervous system, including, in some cases, sexual function.

Almost all the conditions that the MDA supports, by contrast, involve voluntary muscles or the nerves that control these muscles, and little else. Sexual function is largely the result of an interchange of signals among sensory nerves, autonomic (involuntary) nerves, involuntary muscles (including those that line blood vessels and make them dilate or constrict), and the brain (see "How Sex Works," below). People use their voluntary nerves and muscles while making love to enhance their experience and express affection, but these parts of the body aren't in the mainstream of sexual sensation or response.

To be strictly accurate, there are a few exceptions here. There are voluntary muscles in the pelvic area in both sexes (around the vagina and at the base of the penis) that contract during orgasm (see "How Sex Works," below). They contract in an involuntary way, under the control of the autonomic nervous system, but via signals from the voluntary nerves that normally control them. If these muscles are weakened by muscle disease or disorders of the nerves that control them, the strength of orgasm and ejaculation may be diminished. This type of muscle weakness varies in different disorders and even in people with the same disorder.

It should also be said that some MDA-covered conditions do involve systems other than the voluntary nerves and muscles. Charcot-Marie-Tooth disease and Dejerine-Sottas disease involve sensory nerves, and, theoretically, in a severe case, some sexual sensation may be lost. In Friedreich's ataxia, many parts of the nervous system are affected, with sensation affected in varying degrees. The potential for decreased sexual sensation is present.

Finally, two MDA-covered conditions -- myotonic muscular dystrophy and X-linked spinal-bulbar muscular atrophy (X - linked SBMA or Kennedy's disease) -- sometimes show hormonal abnormalities that have the potential to affect sexual function and fertility. In X-linked SBMA, male hormones (androgens) aren't transported into cells in the usual way. This condition, which only affects males, can affect fertility and, possibly, sexual function. In myotonic dystrophy, there are likewise hormonal abnormalities, in this case in both sexes. Fertility is sometimes affected. Men sometimes have atrophy of the testicles, while women sometimes have menstrual irregularities and miscarriages. People with myotonic dystrophy rarely report difficulties with sexual function.

So, although there are a few exceptions, in most neuromuscular conditions, most of the time, sexual function is not impaired.

Myth Number Two
Gradual reduction in ability and loss of interest in sex are inevitable if you have a neuromuscular disease.

EVERYBODY GETS TIRED, ESPECIALLY AFTER A DAY'S WORK IN MIDDLE AGE, AND MOST PEOPLE AREN'T AS SEXUALLY ACTIVE AT 50 AS THEY WERE AT 30. BUT, LOSING ALL INTEREST AND CONSISTENTLY NOT FEELING UP TO HAVING SEX DOESN'T HAVE TO BE TOLERATED, EVEN IF YOU HAVE A NEUROMUSCULAR DISORDER.

Planning and timing, without being too hung up on the idea of spontaneity, is the key. "You have to be a problem solver," says Mitch Tepper, who is pursuing a doctorate in human sexuality education at the University of Pennsylvania. Tepper, who injured his spinal cord as a young man and has since married and fathered a child, likes to remind students that most people plan their lovemaking, and that "the Friday night sex you had in high school or college was one of the most planned events in history." Contrary to popular belief and TV soap operas, he says, "There

isn't all that much sex on the kitchen table happening out there. Some - but not much."

Even if you end up making love less frequently, identify your ideal conditions and time your lovemaking to coincide with them. "Ask yourself, when am I most rested? When do I have the most energy?" Tepper recommends. "Maybe you should decide on some special time, even if it is not as frequent as you'd like. Timing should take into account times when you're not stressed or fatigued."

People with neuromuscular disorders are more likely to develop respiratory and cardiac problems, although they're common in the general population, too. Sexual intercourse generally uses about as much energy as walking three miles an hour, and that can be a strain for people with weakened respiratory or cardiac muscles. Some positions require less energy than others, so experiment. Many people find a side-lying position easier, and some recommend a waterbed. Keep in mind that not all sex has to be intercourse, and not all intercourse has to end in an orgasm.

Of course, respiratory and cardiac problems should be evaluated and treated by a doctor, for the sake of your sex life - and your life.

Weakness of the respiratory muscles, especially the diaphragm, leads to too much carbon dioxide and not enough oxygen in the bloodstream and brain. There are many symptoms of respiratory insufficiency, which is sometimes misdiagnosed as depression. Common symptoms include trouble sleeping at night but trouble staying awake during the day, early morning headaches, difficulty concentrating and remembering, loss of appetite, and a general sense of lethargy and disinterest in things.

One solution is part-time mechanical ventilation through a mask. (There are several types of portable and removable devices.) In any case, the problem needs attention from your doctor.

Heart problems are also common in neuromuscular disease, and your Neurologist or GP is probably checking for these. Loss of your usual energy, difficulty breathing with exertion or chest pain with exertion should be brought promptly to your GP's attention. You may need a referral to a cardiologist. There are some cardiac problems where high-energy sex is ill-advised, but many heart problems can be successfully treated with medication.

And, speaking of medications, some can have unfortunate effects on your sex life. Some drugs prescribed to lower blood pressure and, somewhat ironically, to treat depression, also cause impotence in men. (Reports of their effects on sexual function in women are remarkably lacking.) Blood pressure drugs in the beta blocker family, such as propranolol (Inderal) are common causes of erection problems. Antidepressants in the fluoxetine (Prozac) family, the serotonin reuptake inhibitors, can also cause impotence, as can an older class of antidepressants, the so-called tricyclic drugs. Amitriptyline (Elavil) is an example of one of these.

Of course, drugs that cause nausea, headaches or depression are not likely to enhance your enjoyment in the bedroom either.

If you think you may be taking a drug that is affecting your sex life, check one of the many laymen's guides to drugs available in libraries and bookstores. Check the side effects of medications you're on, and then review them with your GP. Do not stop taking medications on your own, but you may be able to safely switch to a less troublesome product with your GP's guidance. If not, you may be able to time sexual activity to coincide with the trough, rather than the peak, of drug side effects.

Of course, general health has a lot to do with interest in sex for everyone, so eat a well-balanced diet, exercise in whatever way you can (with your GP's guidance), and be sure you're getting enough rest.

According to Dr. Irwin Goldstein, a well-known urologist and author of the book The Potent Male, the same factors that lead to clogging of cardiac arteries in later life - a diet high in fat and cholesterol and low in fibre, little exercise, and smoking - also lead to clogging of the pelvic and genital arteries and to sexual dysfunction, at least in men.

Of course, stress, depression and conflicts in relationships can cause sexual difficulties for anyone, male or female, able-bodied or disabled. If you suspect this kind of problem, try to analyze where the stress is in your life and make constructive changes. Don't hesitate to seek mental health counseling to distinguish among stress, depression, grief or loss and physical problems. Sorting things out alone can be overwhelming.

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Myth Number Three
You, can protect a disabled teen-ager from pain and disappointment by discouraging romantic relationships and ignoring an awakening sex drive.

NOT LIKELY, AND YOU MAY DO MORE HARM THAN GOOD.

Teenagers with most disabilities develop sexual feelings and have increasing needs for intimate relationships in the same way and at the same time as teenagers without disabilities, and these should be respected, within the confines of the family's values.

Many young people with disabilities find and attract partners, and many will go on to have families. Don't assume otherwise.

Jerry Ferro, a mental health counselor in Altamonte Springs, USA, has spinal muscular atrophy and has used a wheelchair since childhood.

He dated in high school, but his parents didn't like the idea. "My parents said, "Jerry, you're only going to get hurt. You don't want to go that way. Just give it up and don't think about it.'" When they thought a relationship was getting serious, they told him, "Don't think about it. Don't call her too much."

Ferro still recalls with some bitterness his father's words shortly before his first marriage. "Now Jerry, what could you possibly have to offer?" Ferro says that question and his parents" general attitude probably hastened an ill-advised betrothal. "I jumped at the first person who fell for me, rather than feeling more confident about my ability to develop a relationship. I said, "Here Dad, take that!'" (He's now in a second, happier marriage.)

Parents need to be supportive, but realistic, as a disabled adolescent begins to develop sexually, Ferro advises. He thinks it's all right for parents to express their concerns but not to be as harsh as his own parents were. "I would have liked some support for my sexuality," he says. "It's really important to support the naturalness of a developing interest in sex in adolescents, and also important to be realistic about limitations. Just as the person with a disability has to adapt to architectural barriers, they also have to adapt to social barriers. That's the key."

Adolescents with disabilities should be given the same kind of sex education that parents feel is appropriate for other children in the family, Ferro says. (See " Resources," below, for some book ideas.)

As a sexual self-concept develops, teenagers also need more privacy than younger children, says Mitch Tepper. "Look for times or ways to give a teenager more privacy," he says. That may include having a hired assistant instead of a parent provide some personal care, and it may mean buying and learning to use more adaptive equipment.

Parents who say they want to discourage a child's relationships because he or she will "only get hurt," Ferro says, "Maybe he or she needs to discover that for themselves. We can't predict the future, nor all the people that they'll meet in their life."

Myth Number Four
Lack of sex is bad for your health.

SEXUAL ABSTINENCE CAUSES NO PHYSICAL HARM.

Myth Number Five
A sexual relationship is the only way to overcome loneliness.

IT ISN'T.

Psychotherapist David K. Reynolds calls this "sleeping sickness" in his book Playing Ball on Running Water,saying people who believe this often sleep with other people in a vain attempt to ward off loneliness and absorb magical powers from their sex partners.

A fulfilling, connected life can be found through non-sexual friendships, communal living arrangements, satisfying work or spiritual faith, as well as through an intimate, sexual relationship. (For a look at modern celibacy through the eyes of a married woman poet who takes up residence in a Benedictine monastery, see Kathleen Norris' The Cloister Walk.)

A decision to lead a non-sexual life is a personal one and a valid one. Make sure it's your choice, however, and not a restriction based on neglected, correctable health problems or acceptance of society's prejudices.

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HOW SEX WORKS

Sexual sensation and function, although it seems simple enough, is actually the result of complex interactions among the sensory nerves, autonomic ("automatic") nerves and muscles, the brain, and to a lesser extent, the voluntary nerves and muscles.

Arousal

Sexual arousal -- what we usually think of as the start of the sex act -- can begin at many points in the system. Often, it begins with touch. Sensory nerve cells (receptors) anywhere on the body, but especially in the erogenous zones like the genitals or nipples, send signals to the brain and spinal cord that indicate that sex is a possibility.

Alternatively, arousal can begin with a sight, sound, smell or even a thought. In this case, the brain starts the process of activating other parts of the nervous system.

In the muscular dystrophies, motor neuron disorders and inflammatory myopathies, sensation and the thinking parts of the brain are generally completely normal, and so is sexual arousal.

The Readiness Response

After the initial arousal event, one part of the autonomic nervous system, called the parasympathetic system, goes into action. The cells of the parasympathetic nervous system, located in the spinal cord, send muscle-relaxing chemicals down their fibers. These chemicals dilate blood vessels in the genital region in both sexes, causing erection of the penis in men and the clitoris in women. The blood vessel dilation is actually caused by relaxation of muscles that line the vessels. This type of muscle, called smooth muscle, isn't the same as voluntary muscle, and isn't ordinarily under voluntary control. (The intestines, uterus and other organs are also partly made of smooth muscle.)

In women, the parasympathetic nervous system chemicals also cause the vaginal walls to secrete a lubricating substance.

All these events can be thought of as getting the body ready for intercourse.

In the muscular dystrophies, motor neuron disorders and inflammatory myopathies, the parasympathetic nervous system and these "readiness" functions are generally completely intact.

Monitoring by the Brain

Meanwhile, the brain is getting signals that arousal and readiness are occurring. At any point, it can either enhance or inhibit the process by the thoughts and images it receives and processes. Thoughts like "I shouldn't be doing this" can have a negative effect and begin reversing arousal. Thoughts like "I really like that perfume" can do the opposite.

The brain is not affected in most MDA-covered conditions.

Orgasm

After a while (sometimes no more than a few minutes), arousal changes. The other division of the autonomic nervous system, known as the sympathetic system, gains control over the parasympathetic system, and begins to set in motion the process of orgasm.

The sympathetic system also has cells in the spinal cord, but they're in a different place and they behave slightly differently. The cells of the sympathetic system normally cause an animal (or person) to tense up to fight or flee from an attacker. They normally increase blood pressure, send blood to the skeletal muscles and stop digestion. Their function in the sex act is a specialized one, however.

Here, the sympathetic nerve fibers carry chemicals that cause contractions in structures in the pelvic area in men, moving semen from these areas into the penis. In women, these same fibers stimulate the uterus and vagina to contract. The muscles that are contracting are mostly involuntary (smooth) muscles.

Usually, within minutes after sympathetic activity begins, muscles in the pelvic and genital area in both sexes contract rhythmically for several seconds. These contractions, which are extremely pleasurable in both sexes, move semen from inside the penis to outside the body in men. Their function in women (other than pleasure) isn't clear. Some of the muscles that contract in this phase are voluntary muscles, under the control of voluntary nerves. These voluntary nerves and muscles are triggered by the autonomic nervous system rather than by conscious intention, however, in a process that resembles shivering. (When the body is very cold, the autonomic nervous system activates voluntary nerves and muscles that increase temperature by causing movement.)

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In people with muscular dystrophy, motor neuron disorders or any other condition in which voluntary muscles are severely weakened, the strength of orgasm could potentially be lessened. This doesn't necessarily occur.

Here again, the brain can interrupt or enhance the experience at any point. Anxiety, depression, dislike of one's partner, or unpleasant physical sensations can all be processed by the brain to stop sexual activity or inhibit orgasm. Positive thoughts, pleasant sights, sounds and smells, and warm emotional feelings enhance the sex act in humans.

Editor's Note: This article was prepared with the help of MDA medical consultant and clinic director Dr. Lawrence Stern of University Medical Center, Tucson, Ariz.

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RESOURCES

Anatomy and Physiology of Sexual Function

Masters, William H., M.D., and Virginia E. Johnson. Human Sexual Response. Boston: Little, Brown and Co., 1966. This one's a classic. Some of the details have been disputed in recent years, but it's still about the best overall reference for this subject.

Masters, William H., M.D., Virginia E. Johnson and Robert C. Kolodny. Human Sexuality, 2nd ed. Boston: Little, Brown and Co., 1985. More of the same, with some later information.

Sex and Disabilities

Heslinga, K. with A.M. Schellen and A. Verkuyl. Not Made of Stone. Springfield, Ill.: Charles C. Thomas, 1974.

Kroll, Ken and Erica Levy Klein. Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (and the People Who Care About Them). Bethesda, Md.: Woodbine House, 1995. Written by a married couple. Kroll has a neuromuscular disorder.

Male Sexual Dysfunction and its Treatment

Goldstein, Irwin, M.D., and Larry Rothstein. The Potent Male: Facts, Fiction, Future. Los Angeles: Price Stern Sloan, 1990. Lots of material on causes, prevention and treatment of male impotence. Written for the general public.

Medication Effects and Side Effects

The PDR Family Guide to Prescription Drugs. Montvale, N.J.: Medical Economics Data, 1993. A layman's version of the PDR (Physician's Desk Reference), which is used by doctors.

Griffith, Winter, M.D. Complete Guide to Prescription and Nonprescription Drugs. New York: Berkley Publishing Group, 1996. Frequently updated.

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For Children Approaching Puberty

Madaras, Lynda. The What's Happening to My Body Book for Girls (and for Boys). New York: Newmarket Press, 1988. Separate books for girls, boys. Suitable for teenagers and older children.

Psychology, Spirituality and Humor

Reynolds, David K., Ph.D. Playing Ball on Running Water. New York: Quill, 1984. A psychotherapist's perspective on modern neurotic problems. Uses principles of Japanese psychotherapy to guide readers.

Norris, Kathleen. The Cloister Walk. New York: G.P. Putnam's Sons (Riverhead Books), 1996. Life in a Benedictine monastery, through the eyes of a woman poet.

Callahan, John. Don't Worry, He Won't Get Far on Foot. New York: Random House (Vintage), 1989. A humorous, excruciatingly truthful account of a young man's struggle to recover his equilibrium after a spinal cord injury.