

SEXUALITY, INTIMACY & CHRONIC ILLNESS

Relationships and sexual satisfaction are important to quality of life. This is especially true for people coping with chronic illness. Sex is an act that can bring satisfaction and release. Even though ALS does not directly affect sexual function, for a person with ALS, sex may also bring pain, frustration and embarrassment. There are methods and techniques available to help people with ALS and their partners cope with their changing sex life and maintain intimacy.

BENEFITS OF SEX

Chronic illness can restrict the activities of daily living. Maintaining a sexual relationship can be a source of comfort, pleasure and intimacy and an affirmation of one's true self when other roles have been stripped away. A satisfying sex life, for the person with ALS and their partner, is one way to feel "normal" when so many other areas in their lives have changed. Documented benefits of sex include the following:

- Orgasm frequency is inversely related to risk of death.
- Reduction of stress.
- Improved sleep post-orgasm.
- Increased relationship satisfaction and stability.

EFFECTS OF ALS ON SEXUALITY

Understanding the sexual response cycle is important to understanding the impact that chronic illness can have on sexual functioning. Sexual function or dysfunction is a combination of physical (due to disease-specific changes or medication or both) and psychosocial factors. Any illness or treatment that affects these factors can have a negative impact on a person's ability or desire to engage in sexual activity.

SEXUAL RESPONSE CYCLE AND CHRONIC ILLNESS

Chronic illness can affect sexual satisfaction and the sexual relationship for both partners. ALS does not impair sexual function but medications, immobility, respiratory problems, fatigue and body image factors may negatively affect sexuality.

PSYCHOLOGICAL EFFECTS

- Anxiety, loss of self-esteem, grief and depression associated with chronic illness may impair sexual fulfillment.
- Chronic illness alters relationship dynamics. Partners become caregivers, as well as lovers. Role changes may cause sexual activity to decrease.

"Sexual health is the integration of the somatic, emotional, intellectual and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication and love".

- World Health Organization Report Series 572; Geneva, 1975.

CYCLE PHASE	FEATURES	GENDER DIFFERENCES
DESIRE	Physiological factors (neurotransmitters, androgens and sensory system) and a variety of environmental stimuli (psychosocial and cultural factors) cause a person to initiate or be receptive to sexual activity.	WOMEN: Touch, verbal stimuli and relationship more important than climaxing. MEN: Visual stimuli more important.
AROUSAL	Parasympathetic nervous system and vascular system involved. Breathing becomes heavier, heart rate and blood pressure increase and an accumulation of blood in the genital region occurs.	WOMEN: Vaginal lubrication and enlargement of clitoris. Men: Penile erection.
PLATEAU	Involves the parasympathetic nervous system & vascular system. Blood accumulation in the genitals at its peak and then levels off before orgasm. Generalized skeletal muscular tension and hypoventilation occur.	WOMEN: Maximal vaginal lubrication and genital blood flow. MEN: Distension of penis is at capacity.
ORGASM	Sympathetic nervous system and muscle tone are affected. For both sexes, there is heightened excitement to a peak of subjective pleasure. A release of sexual tension ensues.	WOMEN: Contraction of uterus and orgasmic platform. MEN: Ejaculation.
RESOLUTION	The body returns to pre-excitement phase.	WOMEN: Ready to return to orgasm with slow loss of genital blood accumulation. MEN: Penis returns to flaccid state

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BIOLOGICAL EFFECTS

- The effects and side effects of some medications can reduce sexual desire and/or the ability to have intercourse or orgasm.
- Reduced cardiovascular and pulmonary function, fatigue or pain can limit sexual activity.
- Medical treatments may alter the person's appearance and bodily function. Psychological distress caused by these changes can limit sexual satisfaction. For instance, people with ALS may feel less desirable if they are using a ventilator or have a feeding tube.

SOCIAL EFFECTS

- Society is uncomfortable with the idea of ill people wanting to have or having sex.
- Although sexual activity may be placed on hold intermittently during the illness, sex remains a vital part of day-to-day living for some people with chronic illness. How can you keep your sex life healthy? Read about your illness. Be informed. Know your body and what feels right in your current state.

PREPARING FOR SEXUAL ACTIVITY

- Plan sexual activity for the time of day when you have the most energy and your health problems are least intrusive.
- Be sure you are rested and relaxed.
- Wait at least two hours after eating to have sex.
- Take any required pain medication 30 minutes before sexual activity.
- Alcohol and tobacco can affect sexual function.
- Reduce or stop taking medications that have a negative impact on sexual functions before sexual activity (on the advice of a physician).

COMMUNICATION

- Develop a system for signalling desire and feedback during activity and direction.
- Prepare advance voice recordings for communication aids.
- Teach your partner how to use these aids while engaged in sexual activity.

SEXUAL DYSFUNCTION

ASSOCIATED WITH CHRONIC ILLNESS

REDUCED SEXUAL DESIRE

IMPAIRED SEXUAL AROUSAL

- Erectile dysfunction in men.
- Lack of lubrication or dryness and coital discomfort in women.
- Lack of subjective pleasure.

ORGASMIC DYSFUNCTION

- Delayed ejaculation or an inability to reach orgasm in men.
- Difficulty reaching orgasm or inability to reach orgasm in women.
- Change in orgasmic intensity.

PAINFUL INTERCOURSE, INCLUDING VAGINISMUS

- Conditioned reflex of the muscles in which they clamp shut.
- Penetration is extremely painful or impossible

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BLADDER AND BOWEL PROBLEMS

- Maintain good hygiene.
- Empty the bladder before sex.
- Employ sexual positions that remove bladder pressure.
- Decrease fluid intake two to three hours before sex.
- Reposition the catheter to ensure proper function.
- Use bladder medication 30 minutes prior to sexual intercourse.

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MAINTAINING A HEALTHY SEX LIFE

- Try alternative ways to experience sex and sensuality. Hold hands, hug, touch your partner and initiate physical contact, even when you do not plan to have sex. ALS does not affect your sensory nerves.
- Use your senses to make sexual activity more enjoyable.
- Communicate with your partner. Be open and honest. Tell your partner what you like and do not like. Listen to your partner's likes and dislikes.
- Try different sexual positions to accommodate your body's changing abilities. Experiment with positions that minimize weight bearing or tiring movements.
- If you are in a wheelchair, consider a model with removable arms.
- Use a waterbed to relieve pressure on joints and to minimize weight bearing positions.
- Try personal lubricants to reduce discomfort during sexual intercourse.
- Book appointments for sex with your partner. Conserve your energy and save it for some intimate time with your partner.
- Consider either self-stimulation or mutual stimulation. Although not acceptable to all people, this provides another method for you and your partner to pleasure one another.
- Orgasms produce a natural high. It helps with pain control and stimulates pleasure producing chemicals in the brain.

SPASTICITY

- A disorder in which certain muscles are continuously contracted.
- Experiment with sexual positioning.
- Take a warm bath prior to having sex.
- Consistently ice sore areas.
- Use anti-spasticity medicines (talk to your doctor about this).
- Massage/stretching.
- Support of joints.

Spasticity during sex can be embarrassing, frustrating and challenging, especially since sexual arousal itself may cause spasms. Bathing in warm water prior to sexual activity may reduce spasticity and relax muscles and joints. The relaxing effects of sex play can help to reduce spasticity and allow for penetration, if desired, once joints and muscles are calmed.

FEMALE POSITIONING

- For men who are unable to straighten their legs, an effective position is with the man on his back, partner on top. The partner can lean back against his bent legs.
- The individual can lie on their side with a pillow or towel between the legs. This position is especially useful when there are knee or hip contractures. Spoon entry from behind works well with this arrangement.

MOBILITY

- Use adapted orthoses, lifts and positioning devices.
- Employ sexual aids and toys; vibrators with hand straps.
- A third party intervention can be called upon to help position both partners.

The individual with ALS often experiences compromised mobility. Adaptations to sexual positions and techniques may be required. Yet, sexual activity can continue to occur and to be satisfying. Sex does not need to involve penis-in-vagina penetration. Penetration does not have to involve the penis. Individuals who are unable to penetrate their partners can employ fingers, hands and sex toys instead. The intimacy and body-to-body contact that comes with penetration can still be reached through other methods:

- Fingering: Using fingers to penetrate your partner.
- Vaginal Fisting: The insertion of an entire hand into your partner's vagina.
- Harness and Dildos: These sex toys can be used to explore vaginal penetration. Men can choose from two kinds of strap-on toys. The first fits over your penis and straps around your waist. The second is a harness that leaves the penis exposed and places the dildo above your penis.

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TO COUNTERACT MOTOR AND SENSORY DEFICITS

- Increase mental arousals (play music, meditate, and practice visualization before sex).
- Increase genital stimulation (practice on self and then transfer to a partner situation).
- Use a personal lubricant.
- Practice positioning prior to sexual activity.
- Explore new ways to pleasure one another without being orgasm-oriented.
- Use sight, sounds and smells. Expand your sexual repertoire to include oral-genital sex, fantasy and sensory experience.

RESOURCES

For the individual diagnosed with ALS and their partner, there are many resources available to help you maintain sexuality and intimacy in your relationship:

- The ALS Society of Alberta has information, books and support programs. They can refer you to counsellors and to in-depth material on the subject. One click (www.alsab.ca) or call (1-888-309-1111) connects you to the ALS Society of Alberta.

WEB RESOURCES

- Rediscovering Sex After Illness or Trauma www.sexual-health.com/article.php?Action=read&article_id=295
- Sexuality and Chronic Pain www.mayoclinic.com/health/chronic-pain/PN00009
- Sexuality: Chronic Illness and Your Sex Life www.family-doctor.org/768.xml
- The American Association of Sex Educators, Counsellors and Therapists www.aasect.org
- The Sexual Health Network www.sexualhealth.com
- www.comeasyouare.com : This website offers modified sex toys for persons with disabilities
- Sex, Love and Chronic Illness. Carlton, Lucille, National Parkinson Foundation, c1994.
- Love and Survival: 8 Pathways to Intimacy and Health. Ornish, Dean. Perennial a division of HarperCollins, c1999.
- Shadows of Pain: Intimacy and Sexual Problems in Family Life. Pillari, Vimala. Jason Aronson Publishers, c1996.

POSITIONING

ONE PARTNER ON TOP

One partner lies on their back with pillows under the knees to keep the legs slightly bent. A rolled-up towel under the back will also work. This position works for almost all sexual activity. Another position is for one person to lie on their front with a pillow under the hips or belly. The partner who has more strength and control may take the position on top with their partner on their back or side.

WHEELCHAIR

A wheelchair with removable armrests offers numerous possibilities:

- Partner on lap facing you with their legs on either side
- For penetration, the partner can sit on the lap of the person in the wheelchair, facing away for a rear-entry position. They can use their arms to support themselves, leaning on your knees.

Wheelchairs without removable arms require different positioning for the partner:

- Partner sits on your lap facing away from you. These armrests can be used for support.

ONE PARTNER ON SIDE

Lying side-to-side is especially effective for an individual wearing a catheter. Both partners can move around without feeling encumbered. Side positions can be used with partners facing one another. This allows both partners to engage in the thrusting movement. When leg or hip tendons or muscles are tight, one partner lies on their side. The other lies perpendicular to their partner with their knees bent over their partner's waist. This is a comfortable position that allows for long and slow penetration sensations.

The mind is the biggest sexual organ. Attitude is everything when dealing with chronic illness and sexuality. Yet, it must be nurtured so that a sexual relationship may occur.