

Living with ALS: Sexuality and Intimacy

Although most people associate sexuality with physical sexual relationships, it is actually a more complex aspect of our lives. Sexual health and sexuality are an important part of everyone's well-being regardless of age, personal circumstances or state of health. Sexuality is an issue for many people with ALS and their partners. Understanding how ALS affects sexuality is the first step to alleviating problems with sex and intimacy that the disease may pose.

How ALS Affects Sex Life

ALS can affect sexual function both directly and indirectly. Its direct effects on nerves and muscles may pose physical challenges and diminish sexual sensation. Its indirect effects – on both the person with ALS and his or her partner – can also interfere with intimacy.

Direct Effects on Sexual Activity

Nerves and Muscles: Sexual function primarily involves the interplay of signals among sensory nerves, autonomic nerves, involuntary muscles (nerves and muscles not controlled by the will) and the brain. To a lesser extent, voluntary nerves and muscles (nerves and muscles controlled by the will) are also engaged during sexual activity. ALS has a direct effect on the voluntary nerves and muscles that enhance the sexual experience. However, while important, these voluntary muscles are not the main source of sexual sensation or response.

Respiratory Function: ALS can weaken an individual's respiratory function, making breathing more difficult and also making sexual activity a strain. Non-invasive positive pressure ventilation (NIPPV) can help, but the equipment needed may create added difficulty.

Indirect Effects on Sexual Activity

Beyond damaged nerves and weakened muscles, other ALS symptoms, as well as some ALS medications, can have an indirect impact on an individual's sex life. Fatigue, lack of sleep, muscle spasms or muscle tightness, and decreased ability to communicate can all affect physical comfort as well as sexual desire.

The onset of ALS can also affect a person's self-image as a sexual being. Individuals who experience depression, anxiety, loss of self-esteem, diminished sexual confidence or negative feelings about bodily changes brought on by ALS may experience diminished sexual function and a decline in intimacy.

Impact on the Partner

The person with ALS may not be the only one experiencing issues with sexuality and intimacy. His or her partner may also be experiencing feelings and psychological symptoms that may affect intimacy and sexual desire. Grief, fear, stress and depression are common symptoms among partners of people who have ALS, and their feelings are sometimes overlooked. If the partner is the main caregiver (which is the case in the majority of couples), exhaustion and resentment over care duties may build up, affecting sexual feelings and intimacy. Switching between the roles of lover and caregiver may also be difficult. Often it is difficult for partners to talk about these issues with the person who has ALS.

Addressing Problems that Affect Sex Life and Intimacy

Communicating with Your Partner

The first step to addressing sexual problems is acknowledging them and understanding them, and then talking about them with your partner. The inability to discuss sex and intimacy with one's partner is often the biggest problem. Avoiding talking about these issues can easily lead to avoiding sex and other intimate contact. Although it may be difficult to bring up the subject of sex with your partner, sharing fears and worries will help you to better understand each other's concerns. Confiding in each other often brings a couple closer and may go a long way toward resolving fears.

Your Healthcare Team Can Help

Talking to your healthcare team about sexual concerns is also helpful. They deal with these issues routinely and you should feel comfortable bringing them up. They can answer your questions and address your concerns, and provide resources and possible treatments. The occupational and physical therapists can suggest ways to minimize discomfort and physical barriers to sexual activities and to help you conserve your energy. If negative feelings are interfering with your sense of intimacy with your partner, psychologists and other mental health professionals can be helpful. In most cases, depression is highly treatable either with medication or therapy (or both).

Redefining Sexuality

Men and women affected by ALS may want to redefine sexuality for their new situation, which will continue to evolve as the disease progresses. Couples may have many ways of exploring sexual feelings with each other, some more adventurous than others. If familiar sexual roles and positions are no longer possible, it may be helpful to talk to your partner about experimenting with new ways to explore your erotic feelings. Again, communicating needs and desires to each other often helps couples become closer and experience a deeper sense of intimacy. Books abound on exploring intimacy and eroticism, and there are even books written specifically to help individuals with physical challenges.

RESOURCES

Books

- **The Ultimate Guide to Sex and Disability, Second Edition**

Mariam Kaufman, Cory Silverberg and Fran Odette (Cleis Press: 2007)

This book is designed for people with a wide range of disabilities—from chronic fatigue, back pain and asthma to hearing and visual impairment, spinal cord injury and multiple sclerosis. Written by a physician, a sex educator and a disability activist, the book covers aspects of sex and disability, such as building a positive sexual self-image, positions to minimize stress and maximize pleasure, dealing with fatigue or pain during sex, and finding partners.

- **Not Made of Stone: The Sexual Problems of Handicapped People**

K. Heslinga with A.M. Schellen and A. Verkuyl (Springfield, Ill.: Charles C. Thomas, 1974).

- **Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (and the People Who Care About Them)**

Ken Kroll and Erica Levy Klein (Bethesda, Md.: Woodbine House, 1995). Written by a married couple. Kroll has a neuromuscular disorder.

- **Sexuality & Disability**

Maddie Blackburn (2002)

- **Sexual Concerns When Illness or Disability Strikes**

Carol Sandowski (1990)

- **Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide**

Marca L. Sipski and Craig J. Alexander (Aspen Publishers Inc: 1997)

This book addresses general sexual function, specific disabilities and illnesses, and treatment concerns.

- **Sexuality and Chronic Illness: A Comprehensive Approach**

Leslie R. Schover, Ph.D., and Søren Buus Jensen, M.D. (Guilford Publications: 1988)

This book reviews basic skills needed to comfortably discuss sexuality with chronically ill patients, assess sexual problems through both psychological and medical approaches, and create a systematic treatment plan.

Counseling

- **American Association of Sex Education Counselors and Therapists (AASECT)**. Provides a list of certified sex therapists and counselors in your area. Address: AASECT, PO Box 1960, Ashland, VA 23005-1960. Tel: 804-752-0026. www.aasect.org

Websites

- **Sexuality Information and Education Council of the United States (SIECUS)** provides a bibliography of print and audiovisual materials related to sexuality and disability. SIECUS, 130 West 42nd St, Suite 350, New York, NY 10036-7802. Tel: (212) 819-9770. <http://www.siecus.org/>
- **The Sexual Health Network** is dedicated to providing easy access to sexuality information, education, mutual support, counseling, therapy, healthcare, products and other resources for people with disabilities, illness or natural changes throughout the lifecycle and those who love them or care for them. <http://sexualhealthnetwork.com>
- The Sex Information and Education Council of Canada (SIECCAN) is a national non-profit educational organization established in 1964 that is dedicated to informing and educating the public and professionals about all aspects of human sexuality in order to support the positive integration of sexuality into people's lives. <http://www.sieccan.org/>
- **Queers On Wheels** is an organization that aids the sexual well-being of the physically disabled community, and welcomes people from all sexual identity groups. <http://www.queersonwheels.com/>