



Sexuality, Intimacy & Chronic Illness

Fact Sheet

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.

"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

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

SEXUAL RESPONSE CYCLE AND CHRONIC ILLNESS

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.

CYCLE PHASE	FEATURES	GENDER DIFFERENCES
Desire	Physiologic 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 and the vascular system. Blood accumulation in the genitals is at its peak and then levels off before orgasm. Generalized skeletal muscular tension and hyperventilation 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

EFFECTS OF ALS ON SEXUALITY

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.

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.

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

Sexual aversion

COMMONLY USED MEDICATIONS THAT MAY IMPAIR SEXUAL FUNCTION

- Benzodiazepines
- Cimetidine
- Lipid-lowering agents
- Lithium
- Monoamine oxidase inhibitors

- Opiates
- Thiazide diuretics
- Tricyclic antidepressants
- Selective serotonin reuptake inhibitors

- 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.

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.

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.

SUGGESTIONS TO HELP YOU PREPARE 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).

"Sex is more than an act of pleasure, sex is the ability to be able to feel so close to a person, so connected, so comfortable that it's almost breathtaking to the point you feel you can't take it. And at this moment you're a part of them." - Sophia Loren

SUGGESTIONS TO HELP YOU MAINTAIN 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 honest and open. 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.

Orgasm produces a natural high. It helps with pain control and stimulates pleasure producing chemicals in the brain.

"The intimacy in sex is never only physical. In a sexual relationship we may discover who we are in ways otherwise unavailable to us, and at the same time we allow our partner to see and know that individual. As we unveil our bodies, we also disclose our persons." Dr. Thomas Moore, "Soul Mates," *Psychology Today*, (Mar/Apr 1994), pp. 28, 29.

THERAPIES AND SUGGESTIONS TO HELP THE PERSON WITH ALS DURING SEXUAL INTIMACY

- Trapped in a body that ceases to respond, too much time to think, sex can be very enjoyable, as everything works fine. If desires are left

unsatisfied, sex can become one more adverse and painful agony to deal with. It shouldn't be that way." - person living with ALS

People with ALS may feel depressed or tired a lot of the time. They may experience pain, weakness, difficulty breathing, problems with co-ordination and trouble sleeping. However, there are ways to combat these issues so that both the person with ALS and their partner can engage in sexual activity.

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 antispasticity medicines (talk to a 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.

POSITIONING FOR THE INDIVIDUAL WITH SPASMS

- 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 lay on their side with a pillow or towel between the legs. This position is especially use-

ful 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 the fingers to penetrate your partner)
- **Vaginal fisting** (insertion of the entire hand into your partner's vagina)
- **Harnesses and dildos** 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.

TO COUNTERACT MOTOR AND SENSORY DEFICITS

- Increase mental arousal (play music, meditate, practice visualization before sex)
- Increase genital stimulation (practice on self and then transfer to a partner situation)
- Use a personal lubricant
- Practise 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.

COMMUNICATION

- Develop a system for signaling 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

BLADDER AND BOWEL ISSUES

- 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

POSITIONING FOR THE INDIVIDUAL WITH ALS AND THEIR PARTNER

One partner on top

One partner lays 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 lay 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.

ACCOMMODATIONS FOR A WHEELCHAIR OR COMMODOE CHAIR

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. The armrests can be used for support.

ONE PARTNER LYING ON THEIR 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 sessions.

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. The following three sexual rehabilitation principles may help maintain a sexual and intimate relationship:

- Maximize the physiology (i.e., reduce fatigue, pain) to achieve optimal sexual benefits
- Adapt to limitations and make adjustments where necessary
- Stay positive and open to experiences

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:

- Your local **ALS SOCIETY** has information, books and support programs. They can refer you to counselors and in-depth material on the subject. One click (www.als.ca) or call (1-800-267-4257) connects you to the ALS society in your area.

WEB RESOURCES

- **Rediscovering Sex after Illness or Trauma**

http://www.sexualhealth.com/article.php?Action=read&article_id=295

- **Sexuality and Chronic Pain**

<http://www.mayoclinic.com/health/chronic-pain/PN00009>

- **The American Association of Family Physicians provides a helpful patient handout titled Sexuality: Chronic Illness and Your Sex Life**

<http://familydoctor.org/768.xml>

- **The American Association of Sex Educators, Counselors and Therapists**

www.aasect.org sources and links to other helpful sites.

- **The Sexual Health Network**

www.sexualhealth.com

- www.comeasyouare.com - offers modified sex toys for persons with disabilities

BOOKS ON SEXUALITY

- **Reclaiming Intimacy in Your Marriage: A Plan for Facing Life's Ebb and Flow... Together.** Bruce, Debra and Robert. Bethany House, c1996.

- **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.

- **The Illustrated Guide to Better Sex for People with Chronic Pain.**

Rothrock, Robert W. et al. R. Rothrock & G. D'Amore Publishers, c1992.

- **Sexuality and Chronic Illness: A Comprehensive Approach.** Schover, Leslie R. and Jensen, Soren B. Guilford Publications, c1988.

WITH SOURCES FROM

- **ALS Society of Canada web site**
<http://www.als.ca/resources.aspx>

- **American Family Physician: Chronic Illness and Sexual Functioning**
<http://www.aafp.org/afp/20030115/347.html>

- **Chronic Illness and Sexuality**
http://www.mja.com.au/public/issues/179_05_010903/mci10673_fm.html

- **Discussing Sexuality in ALS: Staff and Patient Issues**
www.alsmndalliance.org/pdfs/presentations/3%/20%/-20tider.pdf

- Ducharme, S. H., & Gill, K.M. **Sexuality after Spinal Cord Injury: Answers to your questions.** Paul H Brookes Publishing Co. Inc. 1997. Baltimore: Maryland.

- Kaufman, M. M.D., Silverberg, C., & Odette, F. **The Ultimate Guide to Sex and Disability.** Cleis Press Inc. 2003. San Francisco: California.

- **Lupus Foundation of Minnesota**
<http://www.lupusmn.org/Education/Articles/SexandSexualityWithOngoingIllness.htm>

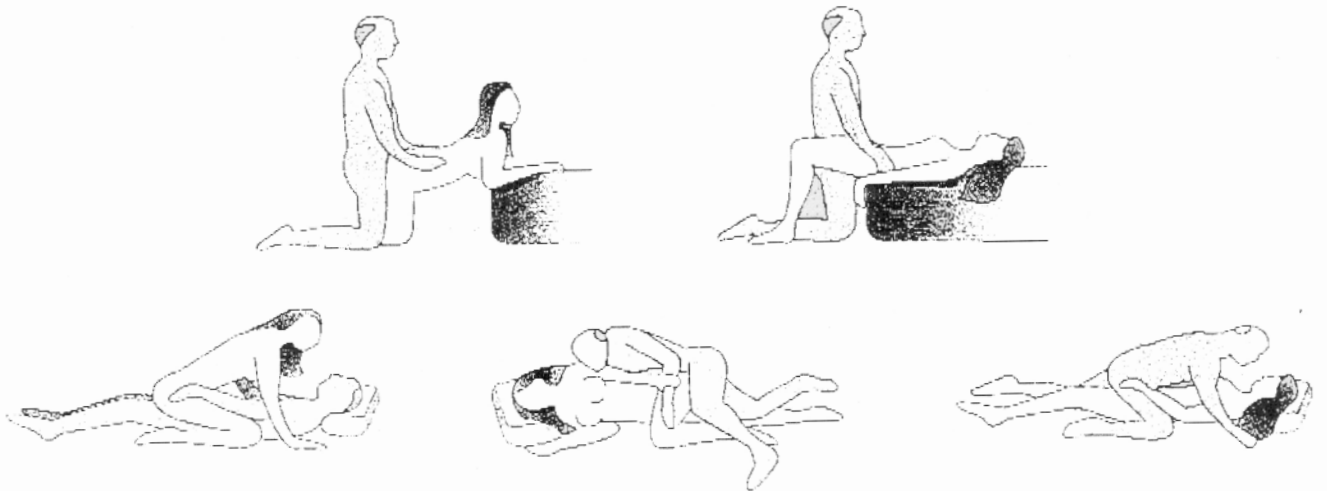
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- **Sexuality: Chronic Illness and Your Sex Life**
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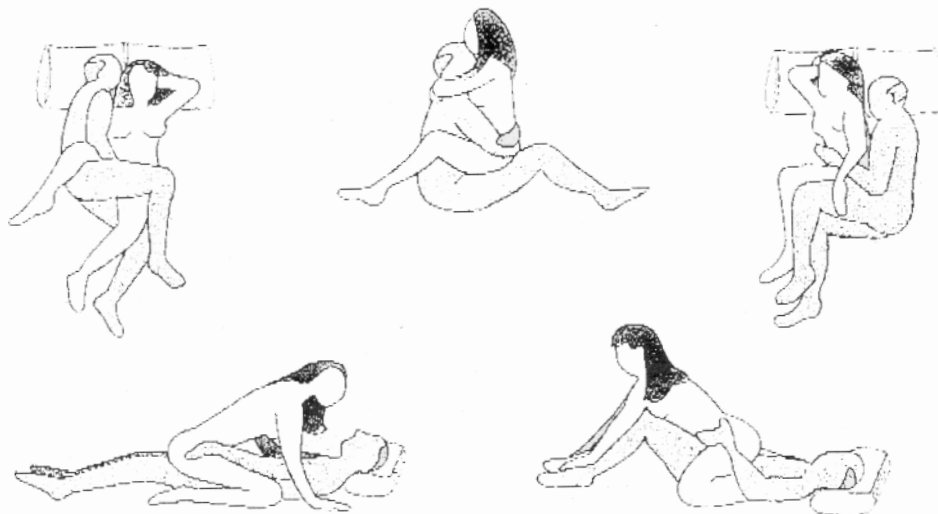
By: Joanna Model

Possible Positions :

1 when the female has respiratory problems.



2 when the male has respiratory problems.



Adapted from Hahn, K. Sexuality and COPD. *Rehabilitation Nursing*; 14: 191-195.