

Sexuality, intimacy and ALS

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It is important for people with ALS to feel closeness and connection with their intimate partners, and to experience healthy sexuality, whether with a partner or solo. While ALS does not affect sexual functioning directly, the disease progression affects mobility, mood, strength, and breathing, so creativity and experimentation may be required to achieve satisfying sexual intimacy.

In addition, people with ALS may be affected emotionally due to the changes in their sex life. They may find something that was once fun and carefree becomes a source of frustration.

This fact sheet has information about how you can maintain intimacy and healthy sexuality while living with ALS.

DOES ALS AFFECT SEXUALITY?

Importantly, the disease progression of ALS does not directly affect the sexual organs or sexual functioning. People with ALS usually respond normally to sexual stimulation, and are able to experience orgasm.

Limb weakness and fatigue arising from ALS create the need for people with ALS to adapt and be creative with some aspects of sexuality.

Many illnesses, including ALS, can have a negative impact on a person's ability or desire to engage in sexual activity, and this can translate to an emotional effect, as well. People with ALS may experience shame or grief surrounding the loss of normalcy around sex.

A study of 62 people living with ALS and their partners found that sexual interest and sexual activity both decreased after the onset of ALS. Couples were also more likely to experience sexual problems following diagnosis.

The sexual problems that people with ALS and their partners reported included a decrease in libido, and passivity of oneself or one's partner. These causes were reported as being due to the physical weakness and body image changes resulting from living with ALS.

THE IMPACT OF ALS ON SEXUAL PARTNERS

Because sexual intercourse takes place between two people, both the person with ALS and their intimate partner can be affected.

Partners of people with ALS may experience some of the same emotions as the person living with ALS, for example, grief over the loss of their previous sex life. These feelings are valid and normal, and it does not make you a bad person to feel them.

People with ALS and their partners can often maintain a sexual connection once they figure out techniques and methods that work for them.

WAYS TO MAKE SEXUAL INTIMACY EASIER

One of the first steps to help make sexual intimacy easier with your partner is to differentiate between caregiver and sexual partner. Often it is the same person playing both of these roles, but it is important to focus on just being the sexual partner during your shared intimacy.

Another very important factor to consider is communication between people with ALS and their sexual partners. Communicating openly about your feelings and challenges before and after sexual intimacy can help make the experience much more enjoyable.

Scheduling an intimate night together may also be helpful for both of you. It can take some of the pressure off by allowing both people to have time to prepare mentally and physically. It can also make it easier to set the mood prior to the experience.

It can help to pay special attention to mental arousal, and setting the mood. You can play music, meditate, or practice visualization before sex.

The use of lubrication can help make sexual contact more comfortable for individuals and their partners.

TIPS FOR POSITIONING

People with ALS may need to explore new positions to accommodate muscle weakness or to decrease their energy expenditure.

Here are some positions recommended by physiotherapists as they expend less energy and work well for people with limb weakness.

Side-by-side

People with ALS and their partners can lay either face to face, or in a “spooning” position where they both face the same way. Positions like this are low impact, but can be highly intimate.

Partner on top

One person sits or lies on their back, while the other lies between their legs or straddles their lap. This position can be highly enjoyable for both people, while decreasing fatigue.

The partner who has more strength and control may take the position on top with their partner on their back or side.

Wheelchair position

A person with ALS can enjoy sexual intimacy while seated in a wheelchair. Not having to change positions can help reduce energy and fatigue as well.

You can remove the side rails on the wheelchair and push the wheelchair up against the edge of the bed. The partner can straddle the person in the wheelchair, and the person in the wheelchair can use the edge of the bed to assist.

Another wheelchair position involves the partner sitting on their lap facing away from the person in the wheelchair with their back to them. This can be referred to as a modified “doggy style” position. This allows the partner to do the majority of the work.

Both of these positions can be helpful for those with limb weakness or respiratory impairment, as you are able to remain sitting up in the wheelchair.

Importantly, not all positions will be appropriate for everyone. People with ALS will need to take into consideration their comfort and safety, and consult with their doctor or an occupational therapist if needed.

OTHER WAYS TO MAINTAIN INTIMACY

It is extremely important for people with ALS to maintain intimacy and healthy sexuality. While sexual expressions of love are one way to accomplish this, people with ALS also have access to many other ways of maintaining intimacy.

Cuddling, kissing, and hugging are all easy ways to maintain an intimate connection with a partner when sexual expressions of love are no longer feasible. People with ALS may also enjoy receiving a massage from their partners, or if they do not have a partner, from a massage therapist.

There are some alternative ways to connect sexually with a partner, including manual and oral sex, in place of intercourse.

People with ALS who do not have an intimate partner can masturbate, and may consider using sex toys to make it easier.

It can also help increase feelings of intimacy for partners to sleep in the same bed or the same room when possible.

WHERE TO GET HELP

You can get advice about sexuality and intimacy from your healthcare provider.

Your primary healthcare provider may be able to discuss this with you, or he or she may refer you to a specialist, like an occupational therapist, physiotherapist or clinic nurse who can provide guidance that is tailored toward your ability level.

Women who have ALS may wish to discuss the use of an indwelling catheter, as opposed to a suprapubic catheter, depending on their sexual experiences. This is something your clinician can educate you on.

SUMMARY

- People with ALS can have enjoyable sexual experiences, either solo or with a partner.
- While ALS may present challenges to intimacy, there are ways to continue to enjoy a healthy sexual life.
- People with ALS and their partners, if applicable, can consider which sexual positions work well for their specific ability level.
- People with ALS can masturbate, and may consider using sex toys. There are products designed for people with disabilities.
- Mental arousal is important, and it can help to set the mood before a sexual experience.

ADDITIONAL RESOURCES

[Sexuality in patients with amyotrophic lateral sclerosis and their partners](#)
[8 accessible sex toys and aids for anyone with a disability](#)

KNOW THAT WE ARE HERE TO HELP I For people and families living with ALS in Ontario, ALS Canada can assist in connecting you to support services, equipment, and ALS clinics. Whether you are a person living with ALS, a family member or a caregiver, we will strive to support you along this journey. If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region. Learn more at www.als.ca.

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