



# ALS & Relationships, Sex and Intimacy

A Les Turner ALS Foundation Guide for Caregivers

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Disclaimer Statement: The information in this guide is not medical advice. Talk to your ALS care team before making any decisions about your health or treatment. Together, you and your care team can find a treatment plan that works for you.

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# ALS & Relationships

Becoming a caregiver for someone with ALS is likely something you never thought you would have to do, and your relationship with your loved one is bound to change. In this guide, you will find tips on how to handle changing relationship dynamics as well as information on ALS and physical intimacy.

Our intention is to provide you with information that you may need today and tomorrow.

## Changing dynamics

Both you and your loved one may sense a shift in the dynamics of your relationship, as you adjust to your new role as a caregiver and the person receiving care adjusts to relying on you for assistance. Every relationship is different and depends on many factors, from previous relationship dynamics to the speed that the disease progresses.

## Changes in thinking and behavior

It is a common misconception that ALS does not impact thinking and behavior. Recent studies show up to 50% of people living with ALS may eventually experience some change in cognitive functioning or behavior. Cognitive and behavioral impairment in ALS can vary from individual to individual. The person living with ALS may experience a change in personality, increased irritability, development of obsessions, and/or decreased insight, all of which can change the dynamics of your relationship.

Your ALS care team is here for you and can help you navigate the challenges that come with cognitive and behavioral impairment. To learn more, read: **Changes in Thinking and Behavior in ALS** by the ALS Association.

### Tips to handle a change in dynamics:



#### **Communicate**

Communicate your needs and allow the person you are caring for to communicate their needs. Your ALS care team and speech-language pathologist can help with communication needs.



#### **Have patience**

Be patient with each other during this time of transition.



#### **Enjoy time together**

Continue to do things you enjoy together! Engaging in meaningful activities together will help relieve stress for everyone.



#### **Accept your differences in grieving**

Try to understand that you and your loved one may be grieving in different ways.



#### **Be honest**

Being honest with your children about ALS can be difficult, but age-appropriate honesty is necessary to maintain trust.

# Creating a fulfilling future

When your loved one is diagnosed with ALS, you will likely wonder what the future will look like with them. You may feel like your future plans have been disrupted and are now unachievable. Although things may look a little different, fulfillment is still possible for you and for the person living with ALS.

## Tips to create a fulfilling life



### Live in the present

Focus on living in the present without placing too much emphasis on what the future holds.



### Don't try to accomplish everything at once

Take things one day at a time and know that you do not have to accomplish everything at once.



### Focus on what you can do

Don't dwell on what you can no longer do. A diagnosis of ALS does not mean your life is over. Focus on making positive memories with the person living with ALS.

# Sex and intimacy

Intimacy is an important aspect of your well-being and is necessary for a healthy relationship. Sexual intimacy can be a significant part of a relationship and is a common issue for many people living with ALS and their partners.

Lack of intimacy in your relationship can lead to emotional detachment from your partner. You may have to redefine what physical intimacy means in your relationship, but it does not have to come to an end.

“ It is normal to feel like both a sexual partner and a caregiver



## Partners of a person living with ALS have reported concerns about

Causing injury

Causing pain

Managing uncomfortable positions during sex

Breathing problems during sex

Wearing their partner out

Pressuring their partner into something they do not feel comfortable with

## Tips for managing ALS and sex



Express your needs and concerns with your partner and let them express theirs



Be open to trying new things



Experiment with accessible aids and toys



Set aside time to be intimate with your partner



Find techniques that work for you and your partner

Your ALS care team can help you come up with solutions to maintain an intimate connection with your partner. If your healthcare provider does not bring up the topic of intimacy, do not hesitate to start the conversation.

**To learn more about physical intimacy with ALS check out the following resources:**

**The Motor Neurone Disease Association's sex and relationships booklet** provides ways to maintain physical contact with limited movement for people living with ALS (MND is another term for ALS). It provides guidance and how to find support, regardless of your sexuality or whether you are in a couple or single. This information can also help you start sensitive conversations with medical or mental health professionals. To learn more, visit: [mndassociation.org](http://mndassociation.org)

**ALS Society of Canada** created this **Fact Sheet on Sexuality, intimacy and ALS**. The fact sheet has information about how you can maintain intimacy and healthy sexuality while living with ALS. To learn more, visit: [ALS.CA](http://ALS.CA)

# Learn more

The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research. To learn more about living with ALS visit, [lesturnerals.org/resources](http://lesturnerals.org/resources).

## My ALS Decision Tool™

If you have ALS, you will need to make some important decisions about your health care. As your disease progresses, your ALS care team may recommend different care options. You can use this tool to learn about some common ALS treatments, answer a few questions to help you think through what is most important to you and get ready to talk with your ALS care team about your options. To learn more, visit: [alsdecisions.org](http://alsdecisions.org).

**MY ALS  
DECISION  
TOOL**

## ALS Learning Series

Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly featuring members of the Foundation's Support Services team, our Lois Insolia ALS Clinic at Northwestern Medicine and other national ALS experts. To learn more about ALS care and research, visit: [alslearningseries.org](http://alslearningseries.org).

**ALS  
LEARNING  
SERIES**

## My ALS Communication Passport to Quality Care

My ALS Communication Passport to Quality Care was created to make your life easier. You will be able to share health information and care preferences with caregivers. You have a lot of information to keep track of, and this tool will help you do that. To find out more, visit: [lesturnerals.org/passport](http://lesturnerals.org/passport).

**MY ALS  
COMMUNICATION  
PASSPORT  
TO QUALITY CARE**

## Support Groups

We facilitate support groups to provide people living with ALS, their caregivers and family the opportunity to share their experiences, give encouragement and help each other navigate their journey with ALS. To find out more, visit: [lesturnerals.org/support-groups](http://lesturnerals.org/support-groups).

