

ALS and Marriage

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Illness, including ALS, can attack without warning and can happen to anyone. No two people with ALS are living in the same situation and no two ALS illness courses will exact the same toll. All couples, however, where one partner is placed in the dual roles of loving partner and personal care provider will experience the greatest test on a marriage and that of their commitment to the marriage. It is essential that couples continue to function as partners and not become only patient and caregiver. The relationship will be changed forever, but it is important to accentuate the positives of this journey and take advantage of the tools that can help preserve this relationship.

With ALS physical changes comes a shift in the balance of power that is naturally created in all relationships. As one partner becomes dependent, the other must "pick up the slack" to make sure that the household functions, the kids are raised and/or cared for, the bills get paid, and the physical care and emotional support for their loved one is provided. The well partner most often needs some extra emotional support to accomplish all of this, but is unable to turn to their partner to meet this need.

Each partner is also grieving, not only for the life of the person with ALS, but for lost dreams and loss in identities as physical losses occur. These losses also bring stress on the changing relationship; caregiving duties are brought to the forefront again.

A loss of privacy is also present to both the ill partner and the well partner. A loss in intimacy can develop if both partners do not do everything they can to honor the choice they have made to travel this journey together as a team. The biggest mistake that a person with ALS can do to destroy this relationship is to live with the thought that my partner can do it alone or that my partner is the only one I will let help me. Another mistake by the PALS is not paying attention to their partner and asking when they need help, not waiting until you think they need help, or making the decision for them. Although this decision protects the PALS, it can directly harm the well spouse both physically and emotionally as well as destroy the bonds of marriage.

Many past caregivers report feelings of anger, guilt, fear, isolation, grief, and financial threat whether they are full-time caregivers or whether their partners have only moderately disabling illnesses. Accompanying those feelings are signs of depression, loss of appetite, sleeplessness, loss of sexual drive, and crying. The act of caregiving itself seems to bring stress, nervousness, and depression with it. Past caregivers also report that maintaining the intimacy levels and fulfilling the sexual attention was described as work, rather than loving acts between two people.

Each caregiver will react differently to the added responsibilities; however at some time during the course of ALS, whether short and rapid progression or a long slow disease course, the changes and grieving can force a shift in the relationship. Both the sick spouse and the well spouse must be cared for.

How to Preserve the Relationship?

1. **Maintain equality** within the relationship and find ways for both partners to make significant and meaningful contributions. Take advantage of the resources available to you. The power of technology can allow a person with very little controlled muscle movement to become an active member of the family.
2. **Keep communication open** through family meetings and make decisions as a team. Remember to try and end the ALS journey as you started it: a team fighting together.
3. **Focus on your relationship.** Research indicates that the better you feel about your relationship with the person receiving care, the less stress you will have. Talk with him or her. Get counseling. If there is serious conflict, invite a third person, one you both know and trust, to help mediate. The results can be gratifying. Spouses with the highest morale generally attribute it to the continuing companionship and good relationship they have with their partners, which can also help sex lives to stay healthy.
4. **Get help!** Take advantage of resources available, especially respite care. This allows caregivers to get away from relentless and potentially overwhelming responsibilities for an hour, a day, or several weeks by having skilled care personnel stay in the home, or by having their partner stay in a facility which provides an appropriate level of care. Most caregivers report that providing personal care for their spouse takes away from the sexual intimacy needed to maintain strong bonds of marriage.
5. **Stay independent** and avoid isolation. Keep in touch with friends; have people over or visit them. Going out independently will help decrease isolation and foster independence. Not many married couples, independent of ALS, spend 24 hours together and do all activities together.
6. **Pay attention** to each other's health, both physical and emotional. Honor each other's need to manage stress, relieve frustration, and grieve by taking enough time for them.
7. **Manage stress.** Stress can cause physical and emotional exhaustion. Its symptoms include diminishing self-esteem, a negative attitude, a loss of concern for others, and a loss of focus on your own life. If left unattended for caregivers, it can lead to burnout. It's real, and it happens!
8. **Get your finances in order.** Regardless of how little or how much you have, get some help sorting through insurance policies, retirement programs, social security, and other government entitlements to find out what there really is to draw on. Keep in mind that specific benefits and programs change from year to year, so re-check periodically. This will help to minimize endless worry about financial strain.
9. **Accept help.** Don't try to manage ALS all alone. Taking advantage of the offers of help that come from family and friends can make time to be set aside as couple time. It is important to continue dating activities or those activities celebrating your love for each other that were in place prior to ALS.

You may not be able to do anything about ALS being in your life, but you can control how it impacts your time, energy, attitude, and quality of life. Finding ways to acknowledge and nurture your personal life will bring new energy and enthusiasm into your life as a partner, patient, friend, or caregiver. Even the strongest individuals and marriages may need extra concern and help along the path of ALS.