

Rules For Coping With Advancing ALS

Below are some tips and recommendations for those couples with one slipping into more advanced stages of ALS. These are based upon personal experience and observation.

1. Stop Trying To Be Everything

You are a spouse, not a caregiver. You took a vow "in sickness and in health" but that doesn't mean you must be the one to do it all. You can't. Nobody can. You should transition now to management, scheduling other people to come do the heavy lifting. Being a spouse, loving your partner, and being together is the most important aspect. Believe me when I tell you what a terrible strain this is on a relationship, and you don't want to add physical exhaustion to your mental and emotional exhaustion.

2. Let It Go

You are your attitude and intellect. Physical ability means nothing. All our bodies are for is life support for the brain that holds the essence of who we are. In the 21st Century we have machines to perform physical tasks we cannot or can no longer do. There is no shame in using mechanical augmentation. In fact, it allows us to continue to be ourselves as defined by our intellect and behavior. It should be admired and appreciated.

3. Stock Up

See above. You need equipment and you should have it and know how you are going to use and integrate it into your daily routine before you need it. Advanced PALS are near-dead weight (never say dead!) and are unwieldy to lift and move. Transfers put the PALS at risk of injury. Transfers also put the caregivers at risk. Mechanical assistance should always be used to safely bear the weight of the PALS during any movement (ie bed->chair, etc.). This means obtain and have available the best lifting equipment you can afford. The best style would be overhead track with an electric winch that provides smooth direct lift. However, always have a pneumatic pump (ie Hoyer) lift for emergencies where electricity is unavailable.

4. Take Care

You may be tempted to try to do everything on your bucket list. Given the anticipated shortening of your schedule, you may be tempted to do it all "right now". Although that seems like a great plan, it is the worst option. You should indeed enjoy yourself, but keep in mind that you have a dwindling and impaired battery. You need to pace yourself so as to maintain your strength and health. Just because your motor neurons are betraying you doesn't mean you should push the rest of your body. There are no "Superman Points". Your body doesn't care. If you don't take care of your health you will just hasten what's called "end stage" (which is either a machine breathing for you or a stone monument bearing your epitaph). Taking care of your health includes carefully following any medical intervention prescribed for or designed by you.

5. Never Give Up

Assuming you have agreed with all of the above, victory is in maintaining your quality of life. We reinvent ourselves continually throughout life and this is no different. This is just another event, another transition, another challenge. We are the product of our minds, and our minds can adjust to any environment. We can therefore continue to enjoy much in life. Staying alive allows you to remain part of a family and a community, and being smart about your survival allows you to be a more effective participant in your family and community.