



## **The Greater Philadelphia Chapter**

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## What Can I Do? Caring About Someone With ALS (Or, how to keep being a friend when you're not sure how)

by: Jennifer Klapper, APRN, BC

- ♥ Let the person talk about their illness if they want to. **Ask open-ended questions** like “What is this like for you? or “It must be hard to come to terms with all this. Are there some things that worry you? **Follow their cue:** if they don't want to talk about it, they'll let you know. It helps to know someone is listening, even if no solution is at hand. Your understanding is most important.
- ♥ Don't feel sorry for the person with ALS. Support their sense of dignity and pride: for instance, talk about what you admire in how they're handling this challenge.
- ♥ Laugh with them, cry with them. Allow yourselves to experience intense emotions if they come up. Feelings pass, but the opportunity to share them with a caring person, even briefly, is a gift to each other.
- ♥ Touch them. They're the same person they always were, and need to be accepted for who they are, despite any changes in how they move or speak.
- ♥ Be honest. Insincere actions and feelings are just as noticeable as ever.
- ♥ Let the person with ALS be silent if they want to. **Talking and interacting may take more energy than they have to spend, but they may still appreciate your companionship.** Your presence may be comforting. Ask them directly! Reading the paper, watching a movie together, or sitting on the porch watching the sunset without saying much may be treasured times.
- ♥ Space your visits and calls. Consistent support is very helpful.
- ♥ Offer childcare. Children need a break from a parent's illness, and the person with ALS and their spouse may appreciate some time alone together.
- ♥ Support the whole family: they are all feeling the effects of ALS.
- ♥ Offer to help with simple chores, like going to the pharmacy, grocery store, dry cleaners, or the library for books on tape. These help the whole family.
- ♥ Continue to be their friend, though this is hard on you, too. An illness doesn't overshadow all the good times you've shared.