

Extracts:

that is one big topic....

I don't think we can ever underestimate the pressure a family is under when a parent becomes significantly ill and dependency roles change. Its far from the normal and everyone will feel the impact one way or another. We can be loved to the core by our spouse but there is no such thing as a perfect CALS or PALS. Care giver or 'patient' there are going to be times when situations get out of control one way or another. We are human and complicated and dealing with such a life changing situation is so stressful.

Remember its not just about our personal needs but everything we do day to day to run a family home. These are things we can do to relieve our spouse of that type of burden. Its not easy but not impossible.

Sometimes we can create stumbling blocks for those around us by not gracefully accepting outside help and put a burden on our family as a result. I regret some of the pressure my own anxiety caused my family when I have faced transitions of not being able to cope and unrealistically expected them to take on those aspects. Some families can take on extended roles in their stride and for some it is too much.

Families! Sometimes they just don't get it but who knows, maybe I would be guilty of that also if I didn't have ALS.

I can tell you what i have been through, i have had ALS so long my family seems to think i will live forever, i am at home every day for 10 hours aday

alone, while my wife works, i can still get around a bit, i have 3 grown kids son that works and 2 girls that are stay at home moms, none of my kids come over to just sit and visit anymore, they all live within 15 miles of me, i will see them if they want something, like to borrow money, or to drop off the grandkids, we get together on holidays, but they do not understand that i am sitting here everyday alone fighting this disease, and it is very stressful, my wife can not even talk to me about my disease, she does not want to think about the future without me, i tell them i feel like i am fighting this disease alone, even my friends do not come by, they say they do not know how to handle it, i say if you love someone as much as they say they love me they would be here to help me through this, i know they have their own lives now, but i may not be here that much longer and they should try a little harder to make time for me, i am not trying to sound like poor me i have nobody, i just would like to have some company from my family and friends, i guess they think just because i have had it for over 20 years i am superman and will be around for ever, just asking for some love and understanding, and some hugs once in awhile, a person can get pretty depressed by himself every day.

My parents have given everything they possibly can to help. My mom is my caregiver. My one brother visit every few weeks but with 7 kids they don't have time for much of anything. My other brother lost his wife to cancer and lives with my parents so my mom can help with his 7 year old. My in-laws bring supper a few times a year. Otherwise we only see my husband's parents and his brother's family on birthdays and holidays. Tim, my husband, decided 9 years is long enough to wait for me to die so he can

move on with his life. He moved me and our son to my parent's house. That way he can see me when it's convenient for him and still do whatever he wants. My friends stopped coming by or asking me to do things after the first few years. The pathetic part is these people all live within minutes of me! I see them at my sons baseball games etc so they know I'm portable. I refuse to ask them to come over. Why should I have to beg for their friendship and time? I realize that not asking for what I want probably hurts me in the long run but I would rather keep the only dignity I have left. No chip on my shoulder :) he he he

The main advise re families I have is that everyone is always keen to help, unfortunately some peoples help actually seems to inadvertently create more stress for the partner,...

MAN, is that ever a universal problem! I have given up on this and my life is so much more peaceful now. I spend my time on forums and that fills my day. I feel for those that don't use computers as it must get incredibly lonely.