

Living With ALS *continued from page 6*

a brace on her leg, to a cane, to a walker, to a manual wheelchair, to assist her mobility. She now uses a motorized wheelchair to navigate around her home and needs a mechanized lift to transfer her from the chair. "It's happened in stages," she says.

Community Home Health provided physical



Pam gets assistance from her caregiver Janice McGuire with the lift she uses to transfer from her wheelchair.

therapists who helped train Kofstad and her family to use different devices. Occupational therapists came and assessed the home and gave suggestions for installing hand rails and other ways to make the home more user friendly for her situation.

Kofstad says she is now starting to lose the use of her left hand, wrist and shoulder, and is losing strength in her right hand. She uses a mechanical grabber to help her reach and hold things she needs. "Everything with ALS is heavy," she explains. "You have complete feeling so you are over sensitive." Her energy level is slowly decreasing; she says she has a limited amount of energy each day and has to pick and choose when to expend her own energy and when to ask for assistance. She says even the simplest things, like rolling over in bed, have become a challenge without full use of her legs.

"There are so many things that are a struggle, but I have a system and I just slow down and try not to get frustrated," she says about the challenges of everyday living. "Because that's not going to help, all it does is take more energy if I get upset about it. I have all day... I'm in no hurry," she says with a giggle.

The rapid progression of the disease creates its own issues. "You go to one stage and you figure it out and you have it under control for a while and then all of the sudden something changes and you need to get equipped with other stuff to help," says Kofstad. "That has been ongoing. Within two or three months something works awesomely and then it's gone." She says The ALS Association has been especially helpful in this regard; they have a lending closet full of donated tools and equipment that people can borrow from.

Kofstad says The ALS Association also arranges for help with medical appointments. "When you're treated for ALS you go in once every three months," explains Kofstad. "It's a four hour visit and eight doctors evaluate me; they each come into my room, one after the other, which is so much easier for me than having to go here and there and all over. They do my speech, my swallowing, my respiratory, my occupational and physical therapy, my nutrition...all in one visit."

She has a caregiver, Janice McGuire, who helps her with her daily routine in the mornings and her daughter-in-law Becky, a stay at home mom, spends a good portion of her day at Kofstad's residence to assist her; her husband Harvey still works during the week days. She receives in-home massages twice a week. She is receiving assistance from a speech therapist and is starting to record onto a computer a word bank of common phrases she frequently uses when speaking, so that when she eventually loses her ability to communicate verbally she can pick the phrases she wants to employ and use her own voice to express her needs or converse with family, friends and caregivers.

Even as her condition deteriorates Kofstad has tried to remain active. She says she misses her job and her co-workers at Pacific University but uses

the internet and phone to communicate with family and friends, utilizing texts and Facebook to stay connected. She has a beautiful back deck where she likes to spend



Pam during a recent outing with friends at the Bear Creek Pub.

time when the weather allows. She meets and communicates regularly with a friend who is also suffering from ALS. She has a motorized scooter she uses to travel from her home near downtown Vernonia so she can go out to meet with friends, go to the bank, the post office, or shopping, or just sit in a park. "I can do everything I need to do in town," she says. "It's important to be as independent as you can." The family recently purchased a wheelchair accessible van so she can be even more mobile.

She is also able to see what she considers blessings in her situation. "I never feel alone and have the Lord with me always," says Kofstad. "He keeps me strong."



Pam with grandchildren Hayden and Emma.

She loves spending time with her family, especially her grandchildren; the youngest love to ride with her in her motorized wheelchair. "My kids and my grandkids have joyfully been willing to help me," she says. "We're still able to have a lot of fun." Her family's commitment to helping her is very visible; she and her family received the "Most Enthusiastic Award" at an ALS awareness bike ride in Mt. Angel last summer.

She has maintained her sense of humor and still smiles and laughs often. She laughed when she told me that she had done the ALS Challenge in the summer of 2014, pouring ice water over her head and helping raise awareness and funding for a disease she knew little about, but was about to be diagnosed with. "I didn't do that this year," she said with a chuckle.

Kofstad is very open, honest and realistic about her situation and graciously invites visitors into her home, to observe her therapy sessions and hear her story. She exhibits an assured sense of dignity that is

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