



ALS Support Group of NW WI

**A Gathering of Individuals Touched by ALS
Share Joy, Sorrow, Laughter, Tears, and Hope.**

**Receiving a diagnosis of ALS is challenging and can be very overwhelming.
The ALS support group provides a safe place where patients, families, friends, and caregivers
Gather to share information, support, and resources with others who understand.**

*Second Thursday of each month, **1:00pm – 3:00pm** At Chippewa Valley
Bible Church in Chippewa Falls*

January Monthly Report - 2014

We started the New Year out with a presentation from Barbara Wheeler - Acupuncturist. She is also a Massage Therapist & into Stress/Pain Management Education. The name of her business is Elements for Healthcare LLC. She works in Eau Claire, WI & can be reached at 715-832-2005 or www.elementsforhealthcare.com. Many of her patients have an interest in pain management that is non-pharmaceutical, a “less-invasive” approach for their health concerns, or an interest in a mind-body-spirit approach to health and wellness care. Ms. Wheeler had handouts for the group & showed us the different sized needles used in acupuncture. We had several follow up questions for her. We still had time after the meeting to ‘catch up’ with other group members as we really do care about one another.

Ask the Doc: Q & A with Edward Kasarskis, MD, PhD

Edward Kasarskis, M.D., Ph.D. is Director of the multidisciplinary ALS Center at the University of Kentucky Neuroscience Center in Lexington, Kentucky, professor in the Department of Neurology at the University of Kentucky, and Chief of Neurology at the VA Medical Center in Lexington KY.

Q: My husband has ALS and recently developed frontotemporal dementia or FTD. I'm worried about how our family gatherings will go over during the holidays this year. I don't know how to explain his behavior to my extended family. Can you also tell me how it is related to ALS and what can be done about it?



Dr. Kasarskis

A: These are important questions. Until somewhat recently, it was thought that ALS would only affect the motor system and wouldn't affect thinking, memory or personality. We now know that some people will also develop changes in personality and mental processes, something that is called frontotemporal dementia or FTD for short. It is also sometimes seen in other degenerative diseases of the nervous system. Neurodegeneration is not restricted to motor neurons but also includes parts of the brain other than the motor cortex.

"Frontotemporal" refers to the front part of the brain (the frontal lobes) just above the eyes and behind the temples (the temporal lobes). When this area of the brain develops problems associated with ALS, people tend to become impulsive, lacking insight into the consequences of their actions. They may have trouble planning ahead for things. Unfortunately, the changes make it more difficult for the person and the family to deal with ALS.

To give you an idea of how a person can be affected by FTD, I'd like to tell you about a patient who had a fairly extreme form of the problem. She had ALS with progressive weakness, difficulty chewing and swallowing but those problems were almost minor compared to the changes in personality she experienced.

A wonderful woman, she had been known to be very organized. As the FTD problem started to emerge, she would sometimes spend the entire day loading and unloading the dishwasher or might absentmindedly leave the stove burners on. Although she was very aware of who she was and where she was, she once ended up walking down the center of a major highway on the yellow line when her intention was just to take a walk in the neighborhood.

Another patient would answer any question we asked her with an immediate "Yes honey," and then struggle to give us the correct answer.

One of the big challenges for the family is that people with FTD are not good at assessing recommendations from the healthcare team; they have trouble looking ahead as they consider treatment. Because they cannot make fully-informed medical decisions, those with FTD tend to be less likely to adhere to ALS treatment recommendations, and thus may not live as long as others who are able to use their frontal brain to think and plan well.

People with ALS who have FTD may also have more trouble using equipment that is helpful in dealing with ALS. For example, we have all kinds of communication devices available such as eye-gaze technology to help people who cannot speak, but those with FTD cannot focus or organize their behavior to be able to use them.

There are special tests done by neuro-psychologists that can be helpful for families. The results can tell you how impaired your family member actually is and in what ways. That information can help you know how you can best deal with the problems.

As for treatment, physicians may also try various medications to see how they may help. Some patients may benefit from medications used to treat Alzheimer's disease. If pseudobulbar affect (PBA) is part of the problem, then Nuedexta® may be helpful. It's worth a try.

Now, to answer your question about what to tell the family. I would suggest you explain what is happening. Understanding the underlying issue should help people respond to your husband constructively with patience and clear communication.

On a pragmatic note, be sure you have power of attorney so you can make any necessary decisions for your husband and can take the lead on finances. You don't want to run into unintended financial problems that could occur if your husband acts impulsively.

Take Good Care
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