

## In My Own Words

by Anne Fergusson,  
PAC Core Team Member

I was on Facebook the other day looking at a site called, *Ask the FTDers*. This site is meant for caregivers to ask people with frontotemporal dementia anything that might be helpful in caring for their loved one. Usually the caregivers ask very important, poignant questions. The other day, someone wanted to know if their loved one actually cared about all the things they were doing for them. It is not unusual for people with FTD to have a flat affect and therefore no real reaction. Having said this, I was starting to feel uneasy and somewhat annoyed. I was reminded that there are several sites for caregivers including books and other publications, but very little is written about how the person with this disease feels.

I was diagnosed with FTD at age 48 and I am now 62. I was an RN and loved my job, but my job left me along with my income. I struggled with a new, unpleasant identity. Massive amounts of medications to control my behavior turned me into a living zombie. I lost friends and family. People, including family, were yelling at me seemingly all the time. I was frustrated, despondent, and embarrassed. I became so distraught that my teenage son found me in the garage with the car engine on. That didn't work, so I ingested mouthfuls of Klonopin at one time, just to dull the mental anguish. Sometimes, I took way too much. Finally, I saw a counselor that really helped get me on the mental healing side of this whole nightmare. Why do I open myself so much to you? I want caregivers to know we appreciate and thank them even when we are incapable for expressing it. But please don't discount that we are struggling also.