

Frontotemporal Dementia Resources for Care Partner Support

*by Sharon Hall,
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Frontotemporal Dementia (FTD) is not something you can do “alone.” I call the FTD care partner community a forest of redwoods, because redwood trees only stand tall because their fine, hair-like roots intertwine to hold each other up, much like those in the FTD care partner community.

Turning to Alzheimers support groups for help leaves you feeling like you do not belong, as the symptoms of FTD are so different than Alzheimers. Because of FTD being a smaller community, many areas do not have a specific FTD support group. This is when you can turn to the internet for support.

When I started on this FTD journey with my husband, I could not find adequate support and suggestions to care for him, and myself. I needed real people living the same disease to help me understand how to live a full life and stay sane, while keeping my husband safe and living a good life.

Here is what I learned. I needed real time support, I needed to “talk” to people. I had a relationship on a [website](#) for caregivers, so I turned to Denise Brown and asked if I could moderate a special FTD Chat. She agreed and I started the [FTD Redwood Chat](#) every Monday and Saturday at 7:00pm ET. It has become a family who loves embracing newcomers.

I then heard Dr. Geri Hall, of Banner Alzheimers, speak at a conference and her suggestions were so helpful. I knew there were so many FTD families who can't get to conferences. I once again went back to Denise and arranged to do a monthly podcast with Dr. Hall sharing information to the entire FTD community in this monthly podcast, [Talking FTD with Geri](#), which occurs every 4th Thursday at 2:00pm ET. They are all recorded for future listening.

I also belong to several private Facebook groups. The ones that offer me the best support are [Frontotemporal Degeneration Info and Support](#) and [The FTD Spouse](#), for those who are a care partner to their spouse. You must request entry into the private groups, feel free to tell the admin that you saw this article.

I also want to encourage you to put an Elder Law attorney on your care team. You can find a certified attorney at the [National Academy of Elder Law Attorneys](#) (NAELA). This is a very important first step in this journey.

Another important step is to let people know what you need. I wrote a letter to my neighborhood when my husband was diagnosed, explaining the diagnosis and giving them a brochure. Everyone said “let me know if there is anything we can do,” so I added a list of things that would help. When I broke my femur last year, this neighborhood supplied us with an evening meal every day for over one month. People want to help, let them.

Last, but not least, arrange for regular respite. My husband attends a day program two days a week. I also arrange a weekend respite for myself every three months. This keeps me sane, do not neglect yourself. Remember to watch as many videos [on Teepa's YouTube Channel](#) as you can, and invest in her DVDs for [FTD](#). They are well worth your time.

Sharon Hall is a care partner for her 95 year old Mom who lives with her and her Frontotemporal Dementia husband (bvFTD). Sharon has become an active advocate on behalf of frontotemporal dementia. She has a page that holds many FTD resources to share with family and friends that can be found [here](#). She has been honored to speak on behalf of dementia care partners at the NIH Research Summit on Dementia Care and Services, as well as many webinars, teleconferences, and podcasts.