Insights from Persons Living with FTD



Help & Support

From the Persons with FTD Advisory Council

I will do my best to:

- Understand my FTD in my life and the lives of others
- Advocate for myself and learn what works and does not work for me
- Learn from mistakes of the community, forgive myself and never give up on myself or others
- · Ask you to be patient with me
- Care for myself holistically and be kind to myself
- Seek your help when I need it as it allows me to maintain some independence:
 - If you see me struggling or putting myself at risk, then ask.

- Ask that you allow me the time to complete my words and sentences when I am struggling:
 - Please don't talk over me
- Realistically manage my expectations
- Contribute to building my care team
- Participate in my care with my medical team and bring my voice into the decision-making process
- Remember I am not failing myself or my loved ones/care partner; it is not me but my disease
- Share AFTD Awareness Cards when out in public (theaftd.org/living-withftd/resources/awareness-cards)

"There is life after being diagnosed with FTD. Yes, we lose a lot of skills and abilities, and our personalities can change dramatically, but I am still me; I can contribute and enjoy life!

This is not an end but a new journey!"