From One Care Partner to Another: Daily Reminders of Strength

Help & Support

From Lessons Learned as an FTD Caregiver session

(Katie Brandt, MM (Massachusetts General Hospital Frontotemporal Disorders Unit); Sandra Gonzalez-Morett (AFTD Ambassador); Dawn Kirby (AFTD Ambassador); Scott Oxarart (AFTD Ambassador); Deb Scharper (AFTD Ambassador)

- Educate yourself on FTD to understand the changing needs of your loved one and resources available.
- You do not have to face this alone. Join a support group to connect with others who understand.
- You are doing the best that you can and that is enough.
- Create a care plan for yourself so that you can care for your loved one.
- Remind yourself that loss of empathy, disinhibition, apathy and compulsive behaviors are symptoms of the disease, that the person can't control.
- Be flexible and manage your expectations.
- Speak up and advocate for what you need.
- Trust yourself. Others will have opinions and suggestions, but you know your loved one and your needs best.
- Build your care team of health professionals, friends, and family.
- Do not assume people do not want to help. They may not know how to ask or offer assistance. The next time someone asks, "let me know how I can help," just pull out the list and have them pick at what capacity they can help.
  - That list can include - watch a movie with person living with FTD, gift cards for groceries or takeout, mow the lawn, make phone calls or research local support, ect.
- Seek help early and know that getting outside help does not equal failure.
- Be proactive in sharing symptoms and changes with the doctor before they escalate.
- Share the diagnosis and educate my local community.
- Listen, document and record your loved one whenever possible to help preserve memories for yourself and others.

The Association for Frontotemporal Degeneration
theaftd.org | HelpLine: 1.866.507.7222 | info@theaftd.org