Partners in FTD
Care
An education initiative from AFTD

What to Do About: **Apathy**

Apathy in FTD can be present at all stages of the disease, affecting a range of everyday activities, including social engagement, household tasks and self-care. The person with FTD may know what they want to do, but have trouble carrying it out due to impairment in initiation, planning and motivation — all functions supported by the frontal lobe. Apathy is among the most challenging symptoms for family and professional caregivers to manage. Effective interventions are individually tailored, rely on environmental strategies, and are delivered with understanding and patience.

Support Positive Approaches

- Reframe apathy as brain-based rather than the result of stubbornness or defiance. Learning about disease-related brain changes helps to maintain the caregiver's empathic connection to the person and reduce frustration and anger.
- Develop individualized activities based on needs and interests that motivate and direct the person: spiritual, emotional, physical, nutritional, intellectual, and social. Follow the schedule consistently and adapt the level of difficulty of activities as abilities change.
- Check your emotions continually and try to maintain a positive tone. People with FTD may have difficulty understanding speech but understand tone of voice and non-verbal communication. Anger and annoyance impede engagement and task performance.
- Practice patience. People with FTD require time to process information and respond to interventions.
- Plan extra time for activities. Rushing impairs performance and adds to frustration for the individual and caregiver.
- Allocate adequate staff time for care activities, as it may take longer to provide appropriate, successful care to someone with FTD.
- Draw the person's attention away from thinking about what needs to be done. Confusion and frustration contribute to inactivity.
- Remember, you cannot change the person with FTD. Concentrate on modifying the environment and the intervention.
- Provide emotional support for family caregivers struggling to engage a loved one. Many feel anger over apathetic behavior, or feel they "aren't doing enough" for the person with FTD, which adds to caregiver stress.

Initiation

- Use external cuing to help a person start an activity.
- Keep it simple. Remember that understanding spoken language is difficult for people with FTD.
- Post reminders or set alarms on a smartphone for someone with early executive function challenges. Sync the reminders to a wearable watch if remembering to look at the phone is hard.
- Present cues through multiple senses including visual, auditory, tactile and olfactory. Reliance on verbal cuing alone will be less effective as the disease progresses; you may have to take more direct action (e.g. put a rake or broom in the person's hand).
- Start an activity side by side with the person (e.g. putting dishes away, folding laundry, viewing family photos) and let them continue on their own.
- Introduce multi-sensory stimulation one sense at a time. If used together they may overwhelm the person's senses and confuse or distract them.
- To encourage someone to shower, use a verbal cue (e.g. "It's time for your shower"), show the resident a checklist or schedule and/or the bathing area, provide lavender aromatherapy soap, and help him to feel the water before showering. Play soft music to create a calm, relaxing environment.
- Create a consistent routine. Do things the same way at the same time of day. Automatic behaviors are easier than those requiring complex thinking.
- Expect repeated, regular cuing to be needed. A person with FTD cannot learn to cue themselves.

Planning

- Develop and post a structured curriculum of individually preferred activities. Include regular rests or quiet time, because the demands of goal-directed activities are fatiguing.
- Modify past interests to reflect the current level of ability, e.g. if they enjoyed playing basketball, provide a small basketball hoop.
- Break down complex tasks into smaller steps.
- Encourage less cognitively demanding activities, e.g. word searches instead of crossword puzzles.
- Use larger items geared toward young children as motor skills decline, e.g. toys for toddlers.
- Arrange a rehab therapy consultation (speech, occupational and physical therapies) for assistance structuring and adapting activities.
- Consider providing just one or two choices to limit overwhelming decision-making.
- Encourage repetitive activities—sorting papers, coins or cards; folding laundry; doing puzzles—as these are consistent with some behavioral symptoms.
- Plan personal care at their “best time of day.”
- Provide the opportunity to stop an activity as needed.
- Create a personalized music playlist.

Motivation

- Turn off the television or radio to reduce competing stimuli.
- Provide praise and positive verbal feedback.
- Assume the benefit of the activity. A bored expression or lack of response does not mean they are not participating or enjoying the experience.
- Offer a favorite sweet or chewing gum as a motivator.
- Use amplified lighting in a room or on a specific object to draw attention to it if goal-selection is impaired.
- Laminate photos for residential or day program staff to shuffle through with a resident to see them in a more personal way.
- Create a checklist that the individual can complete. This may provide a sense of accomplishment.

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