

FRONTOTEMPORAL DEMENTIA INTERVENTIONS

Suggestions for Helping Someone with Frontotemporal Dementia

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TO KEEP IN MIND

1. Please see the handout “**Caring Sheet #13: Frontotemporal Dementia: A Summary of Information and Intervention Suggestions with an Emphasis on Cognition**” by Shelly Weaverdyck. It has much more information regarding Frontotemporal Dementia (FTD), including characteristics, neuropathology, location of brain changes, cognitive changes, emotional changes, behavioral changes, non-pharmacological interventions, medical treatments, and resources.
2. Also, please see two other handouts by Shelly Weaverdyck “**Caring Sheet #19: Intervention Suggestions for Frontal Lobe Impairment**” and “**Making Decisions: Suggestions for Helping a Person with Cognitive Impairment Make Decisions**”.
3. A person with FTD may experience **impulsivity, speech impairment, obsessions, perseveration, reduced insight, a reduced pool of options** for decision making and problem solving, **reduced initiative, poor hygiene, and disinhibition**, among other challenges.
4. A person with FTD may also experience an **improvement in some cognitive functions**, such as those used to produce visual art. It is important to recognize, nurture, and rely on cognitive abilities that remain intact or improve. More information about this is in two handouts by Shelly Weaverdyck “**Recognizing Cognitive Abilities: Suggestions for Recognizing Evidence of a Person’s Cognitive Impairment and Strengths**” and “**Messages about Cognitive Intervention**”. This handout will focus on the cognitive functions that are impaired.
5. Some of the **cognitive skills impaired** as a result of changes in the frontal lobe include the ability to:
 - a. **Do more than one thing at a time**
 - b. **Prioritize what to focus on and pay attention to**
 - c. **Focus** on an object or task and **sustain attention** or concentration
 - d. Get started on a task or thought (**initiation**)
 - e. **Keep focused on a task until it is done; Recognize and stop doing a task when it is done**
 - f. **Switch attention** from one idea or task to another
 - g. **Sense how much time is passing**
 - h. **Recognize the difference between the past, present, and future** and the implications
 - i. **Control impulsive responses** to thoughts and desires; censor what to say and do, “count to ten” before speaking or doing
 - j. **Empathize** with how someone else might be feeling and **anticipate their possible feelings**
 - k. Adapt easily to others’ reactions, emotions, and behaviors
 - l. **Explain and interpret situations and changes**
 - m. See and evaluate their own behavior and appearance and compare them to expectations
 - n. Recognize and **correct mistakes** (in appearance and behavior of self and others)
 - o. Know what they know and that they know it
 - p. **Soothe self** when distressed
 - q. **Make decisions**, especially those that require holding multiple options in mind
 - r. **Follow the logic** of an argument
 - s. Nuance facial expression and body movement to convey meaning and to create uniqueness

- t. Match the expression of emotion with the intensity of emotion experienced (own and others')
6. Some of the **speech impairments** that become increasingly severe throughout the course may include (note that comprehension is often less impaired than speech):
 - a. **Speech errors** – wrong words, unintelligible words, words irrelevant to the topic or each other
 - b. **Word finding difficulty**
 - c. **Person talks less**
 - d. Reduced spontaneity of speech
 - e. Fewer words used
 - f. **Repetition** of limited variety of words, phrases, themes
 - g. Clichés used; difficulty individualizing speech to a situation
 - h. Perseveration (person repeats speech or an action)
 - i. Echolalia in later stages (person says words or phrases just heard)
 - j. Mutism in later stages (lack of speech)
 7. Some of the challenges or **behaviors that may occur** as a result of the cognitive changes include:
 - a. **Impulsivity**; Person is less analytical and more **vulnerable to scams**
 - b. **Reduced insight** into behavior & feelings: their own & others; difficult to convince
 - c. **Difficulty seeing from another person's perspective or imagining how they might feel**
 - d. **Reduced empathy & social tact** in words and actions
 - e. **Getting in a rut** or stuck in a thought or behavior or question; repetitive
 - f. **Withdrawal**, apparent loss of interest in people, work, activities person had found interesting
 - g. **Reduced facial expression**
 - h. **Emotional mismatch**: may express emotions with more or less intensity than they actually feel May show "inappropriate" emotional responses (e.g. anger or laughter) or joke inappropriately
 - i. **Emotional lability**: person may switch emotions quickly and without apparent reason
 - j. **Misinterpretation** of what people say or do or of cues from the environment
 - k. **Reduced problem solving**
 - l. **Difficulty adapting to changes** in plans or in the environment
 - m. Increased or reduced irritability, aggression, sexual behavior, or activities such as smoking
 - n. **Obsessions** (e.g., with food, movements, thoughts, actions, tasks)
 - o. **Easily distracted** by internal thoughts or external objects and movements
 - p. **Reduced abstract thinking**; may need to see an object to understand a concept or request
 - q. **Reduced initiation/ lethargy**
 - r. Discomfort when someone initiates talking to and touching this person at the same time
 - s. **Reduced ability to stop from striking or grabbing someone because they can't control impulses or switch gears quickly**
 - t. **Trouble with the law** (e.g., shoplifting)

SOME INTERVENTION SUGGESTIONS

8. **Protect finances & possessions from scams and illegal activity immediately** (e.g., limit access to money, deeds, and valuables by reducing the amount in the checking account, adding another person to the bank account, keeping most of the cash in the bank; putting valuables in a safe deposit box)
9. **Exercise** (especially in the later stages when this person is stiff and more rigid)
10. **Familiarity** (Use helpers, objects, settings, and words that are familiar to this person)
11. **Assist in making decisions** (See handout identified in #3)

12. **Structure this person's tasks** (e.g., break the task into task steps; do difficult steps for this person)
13. **Structure and mark this person's time with activities and events**
14. **Emphasize consistency and predictability** in:
 - a. Schedule of events and daily routines (in time, duration, and order)
 - b. Doing tasks at the **same time** every day, in the **same order**, and for the same amount of time
 - c. Who is providing care or assistance (same carer or helper each time)
 - d. Doing the task the same way each time: **in task steps, objects, words, movements, people**
 - e. Where events and activities take place
 - f. Environment (e.g., avoid changing rooms or furniture)
 - g. Methods of communication
15. Orient this person to time
 - a. Discreetly alert this person to how long they have been doing something
16. **Environment: reduce the number of people and objects**
17. **Give cues (information) about schedule, task steps, expectations** in a way the person can understand and as often as needed (while communicating, in the environment, with consistency)
18. **Avoid unintentional and mixed cues or information** (e.g., giving a request unrelated to the task)
19. Introduce a shift from one thought or activity to another carefully and slowly; give time
20. Remember that comprehension is usually better than expression of language:
 - a. Talk to this person directly
 - b. Don't talk about this person in front of her/him
21. When communicating:
 - a. **Give time** to start an action, response, or task
 - b. Keep information and requests concrete
 - c. **Get and keep this person's attention**
 - d. **Maintain eye contact**
 - e. Use **fewer words**
 - f. **Use words and sentences that are familiar, short, and simple** (use words they use)
 - g. Put most important messages and content first in your comments
 - h. Put most important words first in a sentence
 - i. Note **body language** and what the body is conveying (yours and others')
 - j. **Use nonverbal forms of communication (point to objects, gesture, model)**
 - k. Use **music**, singing, rhythm to help person move and shift attention
 - l. Be clear and respectful with requests; minimize emotional energy and content of request
 - m. **Explain** what you will and are doing
 - n. Inform this person; give this person cues so they know options of what to do
 - o. Interpret for this person so they can understand what someone is saying or doing
 - p. **Soothe** and reassure the person so they can relax and feel more comfortable
 - q. Ask fewer questions
 - r. Make questions yes/no or ask for opinions
 - s. **Avoid negatives** (e.g., avoid frowning or saying "no", "don't", "can't", "never")
22. Avoid embarrassing this person. Use interventions discreetly to save face.
23. Assess this person for abilities and functions (do not assume this person has all the FTD symptoms)
24. Individualize interventions to this person and to each situation
25. Use speech therapy as needed
26. Address depression and anxiety

27. Address social aspects of this person's behaviors:
 - a. Distress of family/carers regarding behaviors (embarrassment, concern)
 - b. Impact on children and coworkers
 - c. Community awareness, support, law enforcement
28. Educate the family and carers, telling them the above information emphasizing:
 - a. Explanation of the course of FTD
 - b. How to match expectations to this person's specific abilities (this is very important)
 - c. **How to "read" this person** though watching and observing
 - d. Comprehension is usually less impaired than speech
 - e. Carer should **be predictable**: minimize change, do things the same way each time
29. Support family and carer throughout the course
 - a. Address anger
 - b. Educate/remind them FTD is a brain disorder (person is not just being obstinate)
 - c. Prepare for employment and financial implications
 - d. Prepare for future care
30. Remember what is lovable about this person.