

FRONTOTEMPORAL DEMENTIA INTERVENTIONS

Suggestions for Helping a Person Living with FTD

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TO KEEP IN MIND

1. Please see **CAIS handout “#21 Frontotemporal Dementia: Information and Intervention Suggestions with an Emphasis on Cognition”**. It has more details, examples, and information regarding Frontotemporal Dementia (FTD), including characteristics, neuropathology, location of brain changes, cognitive changes, emotional changes, behavioral changes, cognitive and other nonmedical interventions, medical treatments, and resources.
2. Also, please see **CAIS handout “#35 Interventions for a Person with Brain Changes in the Frontal Lobe”** and **other CAIS Handouts** about interventions including, for example, “**#32 Making Decisions: Suggestions for Helping a Person Make their Own Decisions by Addressing their Cognitive Abilities**”.
3. More details and specific interventions (including support strategies) are in the *Cognitive Abilities and Intervention Strategies (CAIS) Intervention Strategies* by S Weaverdyck. For example, see the **Cognitive Intervention Strategies** part (sections **II-Comprehension, III-Executive Functions, and IV-Expressive Functions**). The *CAIS* provides **detailed intervention** strategies that address specific cognitive abilities, the environment, tasks and daily routines, and your communication with this person. These interventions can be **individualized** to a particular person and situation.
4. All of these **CAIS Handouts**, the **CAIS Questions and Interventions**, and other **resources** are on the Improving MI Practices website at <https://www.improvingmipractices.org>
5. See the website for The Association for Frontotemporal Degeneration at <https://www.theaftd.org>
6. Abbreviations are **FTD** for Frontotemporal Dementia and **AD** for Alzheimer’s Disease.

FRONTOTEMPORAL DEMENTIA

7. There are various types of FTD. These are described in CAIS Handout #21 mentioned above. This handout uses FTD to refer to the **behavior variant frontotemporal dementia (bvFTD)**.
8. A person living with FTD will be **unique**. They may experience various symptoms, such as **impulsivity** (a reduced ability to stop themselves from thinking, saying, or doing something), **changes** in language and **speech** (including a reduction in the number of words and difficulty finding the words they want to use), **obsessions**, **perseveration** (continuing to think, say, or do something after it is completed or over), **reduced insight**, a **reduced pool of options** for **decision** making and problem solving, **reduced initiative** (difficulty getting started doing something), **poor hygiene**, a reduced **expression of emotions** at times and an exaggerated expression of emotions at times, and **disinhibition**, among other challenges.
9. A person living with FTD may also experience an **improvement in some cognitive abilities**, such as those used to produce visual art. It is important to recognize, nurture, and rely on cognitive abilities that are intact or improve. More information about this is in two CAIS handouts “**#5 Recognizing Cognitive Abilities: Suggestions for Recognizing Evidence of a Person’s Cognitive Strengths and Needs**” and “**#1 Messages about Cognitive Intervention: Suggestions about the Basics of Addressing a Person’s Cognitive Abilities**”.
10. This handout focuses on some of the cognitive abilities that become more difficult with FTD.

11. Some of the **cognitive skills** that **may become more difficult** as a result of changes in the frontal lobe of this person's brain include the ability to:
- a. **Do more than one thing at a time**
 - b. Prioritize or **know 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**
 - f. **Know** or recognize **when a task is done**; know the **order** of task steps and pieces of information
 - g. **Stop doing** a task **when it is done**
 - h. **Switch attention** from one idea or task to another
 - i. **Sense how much time is passing** (for example, whether they have been doing a task for 2 minutes, 20 minutes, or 2 hours)
 - j. **Recognize the difference between the past, present, and future** and the implications
 - k. **Control impulsive responses** to thoughts and desires; censor what to say and do, "count to ten" before speaking or doing
 - l. **Empathize** with how someone else might be feeling and **anticipate their possible feelings**
 - m. **Adapt** easily to someone else's reactions, emotions, and behavior
 - n. **Explain** and interpret **situations** and **changes**
 - o. **See and evaluate their own behavior** and appearance and compare them to expectations
 - p. Recognize and **correct mistakes** (in appearance and behavior of self and others)
 - q. **Know what they know** and **that they know it**
 - r. **Soothe self** when distressed
 - s. **Make decisions**, especially those that require holding multiple options in mind
 - t. **Follow the logic** of an argument
 - u. **Nuance facial expression** and **body movement** to convey meaning and to create uniqueness
 - v. Match the expression of **emotion** with the intensity of emotion experienced (own and others')
12. Some evidence of abilities regarding language and **speech** that become increasingly difficult throughout the course of FTD, due in part to changes in the temporal lobe (and frontal lobe) of this person's brain, might include:
- a. **Reduced** ability to **produce speech** (note this person will likely be able to understand speech more easily than they can produce speech, even when they can barely speak at all)
 - b. **Speech errors** such as wrong words, unintelligible words, words irrelevant to the topic or each other
 - c. **Word finding difficulty** such as not being able to think of the word they want to use
 - d. **Talking less**
 - e. Reduced spontaneity of speech
 - f. Fewer words used
 - g. **Repetition** of a limited variety of words, phrases, themes
 - h. **Clichés** used; difficulty individualizing their speech to a situation
 - i. Perseveration (this person repeats speech or an action)
 - j. Echolalia in later stages (this person says words or phrases they just heard)
 - k. Mutism in later stages (lack of speech)
13. Some of the **challenges** or **behavior** that **may occur** as a result of the cognitive changes include:
- a. **Impulsivity**; this person may be less predictable, less analytical, and likely **vulnerable to scams**
 - b. **Reduced insight** into behavior and feelings, their own and others; this person may be difficult to convince
 - c. Difficulty **seeing** from **someone else's perspective** or **imagining** how **someone else** may feel
 - d. **Reduced empathy** and **social tact** in words and actions
 - e. **Getting in a rut** or stuck in a thought or behavior or question; repetitive
 - f. **Withdrawal**, apparent reduction or loss of interest in people, work, activities

- g. **Reduced facial expression:** face may look more rigid with minimal expression or movement
- h. **Emotional mismatch:** may express emotions with more or less intensity than they actually feel or may show “inappropriate” emotional responses (for example, anger or laughter) or joke inappropriately
- i. **Emotional lability:** this person may switch emotions quickly and without apparent reason
- j. **Misinterpretation** of what someone says or does or of cues from the environment
- k. **Reduced problem solving, planning, or organizing**
- 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** (for example, 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** or apparent lethargy
- r. Poor hygiene
- s. Discomfort or confusion when someone moves into this person’s visual field and begins speaking at the same time
- t. **Reduced ability to stop themselves from striking or grabbing someone** because they have difficulty **controlling impulses** or **switching gears quickly**
- u. **Trouble with the law** (for example, shoplifting)

SOME INTERVENTION SUGGESTIONS

14. Examine and modify this person’s **environment**, your **communication** strategies with this person, and the timing and structure of **tasks** and routines, as this person changes over time. See below and the resources cited in the beginning of this handout, including those with interventions that address **specific cognitive abilities**. The resources also include a method of identifying an individual’s particular cognitive strengths and needs, so that interventions can be **individualized** to this person and situation. These resources are at <https://www.improvingmipractices.org>
15. **Immediately protect** this person’s **finances** and **possessions** from **scams** and **illegal activity** or **dangerous decisions** (for example, limit this person’s access to money, deeds, and valuables by reducing the amount in their checking account, adding someone else to their bank account, keeping most of their cash in the bank; putting their valuables in a safe deposit box). Reduce junk mail, phone messages and calls, and access to media that is distressing or unsafe. Coordinate this with the family
16. **Exercise** and **walk** to help maintain movement (throughout the course of FTD, and especially in the later stages when this person is stiff and more rigid)
17. **Familiarity** (use people, objects, settings, and words that are familiar to this person)
18. **Assist** in making **decisions** (See CAIS handout “#32 Making Decisions”)
19. **Structure tasks** (for example, break the task into task steps; do difficult steps for this person)
20. **Structure** and **mark** this person’s **time** with consistent or routine **activities** and **events** so they can sense what comes next and where they are with regard to time throughout the day
21. **Emphasize consistency and predictability** in:
 - a. Activities, events, and routines
 - b. The **schedule** of events and daily routines (in time, duration, and order); follow it consistently
 - c. **All tasks:** do at the **same time** every day, in the **same order**, and for the same amount of time
 - d. **Who** is assisting (same person each time)
 - e. Doing the task the same way each time: in **task steps, objects, words, movements, people**
 - f. **Where** events and activities take place
 - g. Environment (for example, avoid changing rooms or furniture)
 - h. Methods of communication
22. Make any changes as necessary as this person’s specific needs and preferences change, but changes as

few and as small as possible

23. **Orient** this person to **time**. Discreetly alert this person to:
 - a. What day and time it is when it would help this person to know such information
 - b. How long they have been doing something
24. **Environment: reduce** the number of **people** and **objects**, including the number of people they must see and interact with, as well as confusing sounds, visual stimuli (such as frightening mirrors or pictures on the wall), and **overheard conversations** among other people
25. Reduce distressing or confusing **news** or **programs** on radio, television, social media, and other media that can be misinterpreted, upsetting, or a source of scams
26. Give **cues** (information) about **schedule**, **task steps**, **expectations** in a way this person can understand and as often as needed (while communicating, in the environment, with consistency)
27. **Avoid unintentional** and **mixed** cues (**information**) (for example, talking about one task when they are focused on another task). Give accurate information, including on signs, notes, and clocks.
28. Introduce a shift from one thought or activity to another carefully and slowly; give this person time
29. Remember that comprehension is usually better than expression of language:
 - a. Talk to this person directly
 - b. Avoid talking about this person in front of this person
30. When communicating:
 - a. **Watch** and **listen** to this person to make sure they understand what you are saying
 - b. **Give** this person **time** to start an action, a task, or to absorb, process, and respond to you
 - c. **Get** and **keep** this person's **attention**. Be the most powerful stimulus they encounter when you communicate with them. Use eye contact or touch if they are comfortable with eye contact or touch. Reduce other noise and distraction. Avoid confusing backgrounds behind you (for example, an open door to the hallway, a busy bulletin board or wall paper, other people)
 - d. If they are comfortable with eye contact draw their eyes to your face as you say their name (for example by putting your face in front of their face at eye level, or by bringing your finger from in front of their eyes to the top of your nose). Use touch if they are comfortable with touch, for example, hold their hand or gently squeeze their hand or arm if their attention wanders.
 - e. **Maintain eye contact** and **touch** if this person is comfortable with eye contact and touch.
 - f. Use **fewer words**
 - g. **Use words** and **sentences** that are **familiar**, **short**, and **simple** (use words they use)
 - h. Put the **most important** messages and content **first** in your comments
 - i. Put the most important words first in a sentence or series of sentences
 - j. Keep information and requests **concrete**
 - k. Be **brief**, **clear**, **calm**, and **respectful** with requests; minimize the emotional intensity and content of your request, especially when they are upset (for example, avoid long explanations; avoid scolding or shaming this person)
 - l. **Explain** what you are doing and will be doing
 - m. Inform this person; give this person cues so they know options of what to do
 - n. Interpret for this person so they can understand what someone is saying or doing
 - o. **Reassure** this person frequently so they can relax and feel more comfortable
 - p. Ask fewer questions
 - q. Make **questions** "yes/no" or ask for opinions instead of facts
 - r. Watch for **body language** and what the body is conveying (this person's, yours, and others')
 - s. Use more **nonverbal** forms of communication (**point** to objects, **gesture**, **model**, and **position your body** so this person can **see** and **interpret it** more easily)
 - t. Use **music**, singing, rhythm to help this person move, speak, think, and shift attention. It can also help this person perform a task more easily or distract them when distressed.
 - u. Do nonverbal activities with this person rather than simply conversing, for example, sort through

- photos or cards, put together a picture puzzle, knit, rake leaves, take a radio apart (safely)
- v. When this person speaks, make sure they **mean what they said**, for example, if they reply “Yes” make sure they meant “yes” (since sometimes they might say the opposite of what they intended to say), or if they say “pip” instead of “pen” try to discern what they had intended to say
 - w. If this person has difficulty understanding what you said try, for example, to **explain it, demonstrate it, or point** to the object that you are referring to
 - x. **Avoid negatives** (for example, avoid frowning or saying “no”, “don’t” “can’t”, “never”). Negatives are likely more difficult to cognitively process than positives. For example, say “That might be fun, let’s talk about it after lunch” rather than “No it’s too cold to go outside”.
 - y. Avoid expecting this person to **do more than one thing at a time**, for example noticing you as you enter their visual field and at the same moment listening to you speak (enter their visual field first, then speak once they’ve focused on you); or expecting them to feel and think at the same time, such as hearing your instructions and changing their behavior when they are feeling embarrassed or angry (address their emotions first, then make your comments once they are calmer and focused on you)
31. Avoid embarrassing this person. Use interventions discreetly to **save face**
 32. **Assess** and **support** this person’s **specific** cognitive **skills** and ability to understand, communicate, and perform tasks
 33. Rely on this person’s cognitive and other strengths and support or compensate for this person’s cognitive and other needs
 34. **Individualize** interventions to this person and to each situation. Don’t assume this person has all of the symptoms of FTD. Each person is different
 35. **Assess** this person’s abilities, needs, and desires **frequently**, and **adapt interventions** as the FTD progresses, this person changes over time, and circumstances change. Modify your expectations of this person.
 36. Use speech therapy as needed
 37. Address **depression** and **anxiety**
 38. Address **social aspects** of this person’s behavior:
 - a. Distress of this person, family, and others regarding behavior (embarrassment, concern about effects of the behavior)
 - b. Impact on this person’s family, children (possibly teenagers), and coworkers
 - c. Community awareness, arrange support, communicate with law enforcement to explain this person’s FTD
 - d. Vulnerability to scams through the mail, phone, television, radio, news sources, and social media
 39. Discuss with or explain to this person, family, or others. Include 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. To remember this person can likely understand your words more easily than they can speak (so don’t speak in front of them as though they aren’t there; include them in conversations)
 - e. To **be predictable**: minimize change, do things the same way each time
 40. **Support** this person, family, and others throughout the course
 - a. Address anger, pain, surprise, and other feelings
 - b. Educate and remind them FTD is a brain disorder; this person is not just being stubborn or “mean”
 - c. Prepare for employment and financial implications (especially since this person is likely younger than most people living with dementia)
 - d. Prepare for future care
 41. Remember what you **like** and **admire** about this person