

## Frontotemporal Dementia

Common Behaviors	Approaches
<p><b>Disinhibition:</b> impulsive behavior without regard for how it may affect others. No filter. Loss of recognition of social norms.</p> <p><i>Examples:</i> theft, vulgar language, sexually inappropriate behavior, getting too close or personal, laughing at things that are not funny, inappropriate judgement of others.</p>	<ul style="list-style-type: none"> <li>– Tell family and friends about the diagnosis and what it means.</li> <li>– Avoid situations where problems may occur.</li> <li>– Go to places (e.g. restaurants) where you have informed them of your situation.</li> <li>– Position person between family/friends and/or sit person in a corner when dining out.</li> <li>– Distract the person if potential outburst appears imminent.</li> </ul>
<p><b>Apathy:</b> lack of interest in or unable to initiate activity. Loss of drive. Is not depression.</p> <p><i>Examples:</i> unable to plan the day, unable to complete or initiate tasks, unable (rarely able) to initiate conversation, lack of empathy and compassion.</p>	<ul style="list-style-type: none"> <li>– Provide consistent daily structure and routine.</li> <li>– Gently, physically assist with initiating an activity.</li> <li>– Make eye contact; give instructions slowly, simply and one step at a time.</li> <li>– Make use of body language and pointing along with verbal cues.</li> </ul>
<p><b>Perseveration:</b> repetition of a word, phrase, gesture or act to an abnormal degree. Person seen as “stuck”.</p> <p><i>Example:</i> repeating one word or phrase over and over.</p> <p><b>Obsessions:</b> frequent preoccupation with a specific idea or thought.</p> <p><i>Examples:</i> repetitive discussion of a topic, repetitive requests.</p> <p><b>Compulsive behavior:</b> an uncontrollable urge to perform a repetitive act.</p> <p><i>Examples:</i> humming, pacing, picking at self or objects, persistent wandering.</p>	<p><b>Approaches are the same for all three behaviors.</b></p> <ul style="list-style-type: none"> <li>– Safety first – if it is not dangerous to the person or others, let them do it.</li> <li>– Use distraction to refocus behavior.</li> <li>– Try humor to decrease frustration of both caregiver and person.</li> </ul>

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<p><b>Utilization Behavior (also known as Stimulus Bound Behavior):</b> uncontrollable impulse to manipulate objects within visual field/reach. No regard for someone else using the object. Can result in the need to explore and use everything in the environment.</p> <p><i>Example:</i> The task at hand is to paint a wooden shelf. Instead the person grabs a hammer and nails the shelf to the wall.</p>	<ul style="list-style-type: none"> <li>– Enrich the person’s living environment with appropriate activities and things to manipulate. Such as: picture books, photo albums, puzzles, word search, simple crafts and assembly activities.</li> <li>– Supervise in potentially dangerous environments or activities.</li> <li>– Have only needed items in reach for each step of an activity.</li> </ul>
<p><b>Hyperorality:</b> compulsive eating; eating without regard for being full.</p> <p><i>Examples:</i> eating food off someone else’s plate; seeking additional food after finishing a meal.</p>	<ul style="list-style-type: none"> <li>– Enforce portion control by not placing bowls or containers of food on dining table.</li> <li>– Lock up food (cupboards and refrigerator); out of sight out of mind.</li> <li>– Distract with other activities.</li> </ul>
<p><b>Aggression:</b> physical or verbal behavior that is intended to harm another individual. May occur when told what to do or when redirected. Happens due to lack of insight and ability to see others’ points of view.</p> <p><i>Examples:</i> foul language, shouting, physically striking out, verbal threats.</p>	<ul style="list-style-type: none"> <li>– Seek safe place first; call 911 if a threat to self or others.</li> <li>– Do not argue or attempt to reason; respond matter-of-factly or do not respond.</li> <li>– If not a danger to self or others, give person time and space to calm down.</li> <li>– Distract only if attempt to distract will not escalate behavior.</li> </ul>

## General Caregiver Tips for all Behaviors

- **Try not to take behavior personally.** The person has no insight into their illness or behavior. Consequently, you will not convince them that they have problems. Inappropriate and difficult behaviors are all part of the disease. The person has no control over their behavior or their reaction to their environment. Person is not acting this way to deliberately be difficult.
- **Work on building emotional support for yourself with other people.** The person with FTD may have no empathy for you, for the challenges you face together, or for your caregiving efforts. Consequently, you may feel a loss of previously experienced trust, intimacy and partnership.
- **Break tasks down into manageable steps.** Give minimal choices. Give explicit one step directions in sequence as the person is doing the task. May need to cue to go or start.
- **Do not argue.** Respond matter-of-factly, distract, or do not respond at all. Be gently directive. Be calm. Speak slowly and clearly.
- **Hand out “business cards” that explain your companion is living with brain change.** Use selectively when in public places.