

CHANGES IN BEHAVIOR

Significant changes in behavior and personality are the main symptoms of bvFTD. This means that a generally active, involved person could become apathetic and disinterested. The opposite may also occur. A usually quiet individual may become more outgoing, boisterous and disinhibited. Personality changes can also involve increased agitation, irritability, anger and even verbal or physical outbursts toward others (usually the caregiver). Not all patients will adopt one or another symptom. Symptoms don't occur in "stages" but rather existing symptoms will worsen and new symptoms may appear in an unpredictable manner. Remind yourself that these are not the behaviors of the person you love- ***These behaviors are a result of an illness.***

BEHAVIOR	EXAMPLES	SUGGESTED INTERVENTIONS
<p><u>Apathy/Lack of Motivation</u></p> <ul style="list-style-type: none"> Lack of interest, drive and/or inability to initiate activity Often confused with depression 	<ul style="list-style-type: none"> A person can no longer take the steps to go on a bike ride on their own, but if guided to a stationary bike, they will engage in riding. A person can no longer follow the steps to make a bowl of cereal. However, if the objects involved are laid out for them, and they are cued appropriately, they can execute the numerous steps involved. 	<ul style="list-style-type: none"> Don't rely on the person to initiate activities on their own. While they might have trouble starting an activity, they may be able to participate if others do the planning/divide the task into small successive steps and provide assistance when needed. Limit and offer specific choices; e.g. "Do you want to walk to the park or to Jim's house?" instead of a more open-ended "What do you want to do today?" If they resist, do not force the activity.
<p><u>Perseveration</u></p> <ul style="list-style-type: none"> Repeating the same activity over and over when it no longer makes sense to do so 	<ul style="list-style-type: none"> Repeatedly do the laundry even if there is only one item to wash. Continuously talking about the same topic over and over. 	<ul style="list-style-type: none"> Distract by getting their attention focused on something else. Do not feel you need to explain why. If the activity is not dangerous or costly, let them do it.
<p><u>Disinhibition</u></p> <ul style="list-style-type: none"> Acting impulsively without considering the social effects of inappropriate behavior. Lack insight that the behavior can offend others/cause harm 	<ul style="list-style-type: none"> Making offensive comments to others or to strangers. Speaking about personal issues with strangers. Approaching other people's children as if they were acquainted, or hugging and kissing children. Shoplifting. 	<ul style="list-style-type: none"> Let friends and neighbors know about the diagnosis so they understand the behavior is not intentional. Go to places where person is known well. Distract by getting their immediate attention onto another activity. It's ok to be firm by ending the conversation with, "Thank you, we have to go now," even though it may seem abrupt. Use "The person I am with has FTD" card.

<p><u>Lack of Empathy/Emotional Changes</u></p> <ul style="list-style-type: none"> • Showing no emotions- seeming flat and disinterested • Showing exaggerated jocular or improper emotions. • A lack of sympathy or compassion to others' distress 	<ul style="list-style-type: none"> • Seems to withdraw in familiar company. • Displays emotions that are inappropriate- e.g, laughing at a funeral. • Seems to “not care” about other’s distress. • Seems indifferent to spouse with a diagnosis of cancer. 	<ul style="list-style-type: none"> • Although it is very difficult, <i>do not take this personally.</i> • Find emotional support and companionship from other friends/family or support group. • Seek professional counseling. • Let others know about the diagnosis so they are not offended.
<p><u>Utilization Behavior</u></p> <ul style="list-style-type: none"> • Difficulty resisting impulses to operate or manipulate objects that are within reach • “Automatic” behavior, the kind of action we have all experienced when an elevator door opens and you automatically exit despite the fact that it is the wrong floor 	<ul style="list-style-type: none"> • Seems to be drawn to objects or actions in the immediate environment (e.g., picks up objects that are part of others’ activities, seems to imitate other others’ behaviors) even when those objects or actions are not purposeful or appropriate for the moment. • Picking up the phone when walking by it even if it is not ringing or there is no intention of making a call. 	<ul style="list-style-type: none"> • Determine if the behavior is putting the person or others at risk. If so, distract with other objects that get the person’s attention immediately, such as calling them on a cell phone to interrupt an activity—the person is likely to answer it because that is automatic behavior. • Note that calling their name may not work to get their immediate attention.
<p><u>Hyperorality</u></p> <ul style="list-style-type: none"> • Compulsive eating • Craving carbohydrates or sweets and no ability to regulate intake or “feel full” 	<ul style="list-style-type: none"> • Taking food from someone else’s plate at a dinner table. • Gorging on food to the point of vomiting. • Eating anything in sight with no consideration to how much eaten. • Eating uncooked meat from the fridge. • Eating only a certain type of cookie. 	<ul style="list-style-type: none"> • Provide supervision while eating, setting out portions. • If necessary, lock up foods and keep raw foods out of sight. • Use distraction.
<p><u>Ritualistic/Compulsive Behaviors</u></p> <ul style="list-style-type: none"> • Acts that are completed over and over again, without purpose and unrelated to the circumstances in which they occur 	<ul style="list-style-type: none"> • Person needs to continuously walk on the same route for 2 hours every day at 2pm. • Continuous whistling, drumming fingers in certain patterns. • Rigidity and inflexibility, and insistence on having his or her own way, increasing difficulty adapting to new or changing circumstances. 	<ul style="list-style-type: none"> • If it is safe, accept the behavior and arrange for necessary supervision. • If unsafe (scratching at a sore until it bleeds), consult with a physician to consider medications that can minimize compulsive behaviors.

<p><u>Aggression</u></p> <ul style="list-style-type: none"> • Because many individuals with FTD are not aware of their illness, they may become frustrated at limitations and constraints that they do not understand and consider to be unfair and punitive. As a result, the person may occasionally strike out at the caregiver or resist assistance. 	<ul style="list-style-type: none"> • Shouting, name-calling or physical abuse (hitting, pushing). • These behaviors can occur suddenly, with no apparent reason, or can result from a frustrating situation. 	<ul style="list-style-type: none"> • Stay out of the person’s way if they are combative. In extreme cases, call police but explain the person with FTD’s condition. • Never point out the problem to the person, try to reason about their behavior, or argue about the “logical” solution.
<p><u>Reasoning</u></p> <ul style="list-style-type: none"> • Not able to categorize information or think in the abstract; very literal interpretations • Lacks flexibility in thinking and unable to pursue an alternative solution if the first one doesn’t work • May increase safety risk since they have difficulty recognizing consequences of behavior 	<ul style="list-style-type: none"> • Person cannot understand explanations about their own illness and is resistant to continued attempts to make things clear. • May behave as if the caregiver is “bossy” or unreasonable or trying to control them. • Cannot reason logically about the solutions to simple problems (e.g., how to respond in the event of a fire). 	<ul style="list-style-type: none"> • <i>Do not argue. No amount of reasoning will make the person able to grasp the ideas.</i> • Instead, distract. Tell them firmly what is going to happen and repeat the information from time to time, without explanation. E.g., “We are going to see a lawyer to make sure that we have the proper documents to sell the house.” If asked for an explanation, say, “We will both have time to talk.” • Make sure that all legal steps have been taken to protect the person and obtain power of attorney so that decision-making is not left to the person with significant reasoning deficits.

General Communication Tips

- Always avoid confrontation. This can be done by not arguing or trying to point out the truth.
- Try not to take the person’s behavior personally. There is no intent to hurt but only the inability to have normal reactions and feelings.
- When it’s helpful for the person, keep decision making to a minimum. Don’t put the person in a situation that stresses failing reasoning capacity.
- Approach the person with a calm, reassuring tone. Smile. Individuals with frontotemporal dementia are better at understanding positive emotional expressions than negative ones. So if you are frowning or looking sad or angry, the person may not understand. Alternatively, the caregiver’s emotional facial expression can elicit the exact same expression in the patient even though the patient is not feeling that way but is showing imitative behavior. But a smile will elicit a more positive response.

Meaningful Activities

- Provide materials that are readily available and not dangerous. Jigsaw puzzles, drawing materials, coins to be sorted, laundry to be folded.
- The person should be provided with physical activities within their capacity. They may require support, such as a “trainer”, an individual who can be hired to take the person out for a walk daily, but also to do other types of stimulating activities. Using such a label for getting the proper assistance the patient needs may be more acceptable to the patient than a “companion” or a “caretaker.”

When the individual with behavioral changes shows new symptoms, don't assume that it is the disease. Because patients find it increasingly difficult to articulate such things as pain or discomfort, they may manifest such things as agitation or irritability. It could be the disease or it could be something else that could be addressed with a visit to the primary care doctor. With all new behaviors that you observe, go through the following checklist to determine what is causing the change and find the most appropriate intervention:

- Could this be a separate **medical problem** that is causing the change in behavior? For example, the person may have a toothache but be unable to articulate the precise problem. Another example is an imbalance of thyroid function or other chemical imbalance in the body that temporarily makes the dementia symptoms look a lot worse.
- Identify triggers of certain behaviors -Is the **environment** triggering the behavior? Although many behaviors are erratic and have no explanation or precedent, some may be reactions to certain types of situations. For example, the person becomes agitated when there are more than three people talking. If so, what in the environment can be changed? In this example, the solution might be to reduce the number of people the person interacts with at one time. Invite one adult child and the grandchildren to dinner instead of the whole family. Try to identify if there are triggers and what they might be.
- Is this behavior **safe for them**? Is this **safe for me/others**? Some behaviors are very annoying but are not injurious to the person or others. On the other hand, if the person does not recognize that an 18-month old child cannot be left on the living room floor with the front door open and a flight of stairs not far away, precautions need to be taken to make sure that the person is not put in a situation where they cannot exercise judgment. Even though the patient may be able to play with the 18-month old in an appropriate way, they are unable to be left alone with the child in this instance.

When to consider medications

- Trying the above strategies is always the first step in responding to changing behaviors; however, sometimes medications can also help. Some serotonin reuptake inhibitors are often prescribed for carbohydrate craving, disinhibition and impulsivity. Persons who experience uncontrollable aggression or delusions are sometimes prescribed low doses of antipsychotic medications. It is important to consult with a specialist in this area such as a psychiatrist with expertise in dementia and pharmacology.