

Behavioral Variant Frontotemporal Dementia

People with behavioral variant frontotemporal dementia (bvFTD) often have trouble controlling their behavior. They may say inappropriate things or ignore other peoples' feelings. bvFTD may affect how a person deals with everyday situations. bvFTD can also affect language or thinking skills. Unfortunately, people with bvFTD rarely notice these changes.

What Causes bvFTD?

The cause of bvFTD is unknown. Scientists know that in bvFTD there is a large build up of one of three kinds of protein within brain cells: tau, TDP-43 or fused-in sarcoma (FUS). These proteins occur normally, but we do not yet understand why they build up in large amounts. As more and more proteins form in brain cells, the cells lose their ability to function and eventually die. This causes the affected parts of the brain to shrink.

How is Age Related to bvFTD?

Most people with bvFTD start having symptoms in their 50s, although some people have shown signs earlier or later.

What Happens in bvFTD?

People with bvFTD have increasing trouble controlling their behavior. In the first several years, a person with bvFTD will likely show marked behavioral changes such as apathy, lack of motivation, loss of sympathy or empathy for others and overeating. Apathy is often the first symptom reported by caregivers and may be mistaken for depression. Problems with planning, organization and sometimes memory are evident, but the individual is still capable of managing household tasks and self-care with minimal help. Social withdrawal, apathy and limited interest

in family, friends and hobbies may become evident. At times, they may behave inappropriately with strangers, lose their social manners, act impulsively and even break laws. People experiencing these changes may become self-centered, emotionally distant and withdrawn. They may stop caring about their personal appearance and become increasingly unkempt. Impulsive behavior is another common complaint from caregivers who may find the changes in social and personal conduct embarrassing or frustrating. These behaviors are often associated with a lack of inhibition, resulting in inappropriate behavior, such as temper tantrums, touching strangers, public urination or diminished social tact. Overeating is common and “food fads” can occur where the person with bvFTD will only eat certain foods. Care partners often notice an overactive sweet tooth. Restlessness, irritability, aggressiveness, violent outbursts or excessive sentimentality are not unusual either. But at this stage, the behaviors can often be managed with lifestyle and environmental changes (read our [practical tips](#) for ideas). An MRI brain image at this point will likely show mild atrophy in particular areas of the frontal lobes.

Due to their impaired judgment, people with bvFTD can fall prey to scams, online or in person. As the disease progresses, this lack of judgment may lead to criminal behavior (such as shoplifting, indecent exposure, running stop lights, poor financial judgment or impulsive buying). At the extreme, the impulsivity can be self-destructive, as when patients try to get out of a moving car. In some people, inappropriate sexual behavior occurs.

There may also be repetitive or compulsive behaviors that may include hoarding, doing the same thing over and over (for instance, reading the same book several times or walking to the same location again and again), pacing, or repeating particular “catch phrases” over and over.

The person with bvFTD may experience false thoughts (delusions) that are jealous, religious or bizarre in nature. Or they can develop a euphoria – excessive or inappropriate elation or exaggerated self-esteem.

Over the course of a few years, the symptoms seen in the mild stage will become more pronounced and disabling. You might also notice compulsive behaviors like repetitive urination, hoarding or collecting objects, compulsive cleaning or silly repetitive movements (like stomping on ants). Binge eating may create weight problems and other health issues. The cognitive problems associated with dementia become more pronounced, with mental rigidity, forgetfulness, severe deficits in planning and attention and difficulty understanding conversations. The MRI image at this point will show that the shrinking of the brain tissue has expanded to larger areas of the frontal lobes, as well as the tips of the temporal lobes and basal ganglia, deeper brain structures involved in motor coordination, cognition, emotions and learning.

Even though they might complain of memory disturbance, people with bvFTD can usually keep track of day-to-day events and understand what is going on around them. Their language skills and memory usually remain intact until late in the disease.

Problems with language and other thinking skills can also happen in bvFTD. People may start speaking in shorter phrases and may eventually lose their ability to speak. Sometimes, people with bvFTD may have weakness in their muscles, difficulty swallowing, or difficulty walking.

These behaviors have a physical cause and are not something that the person can usually control or contain. Indeed, often the person has little or no awareness of the problem behaviors.

bvFTD is a disease that changes with time. A person with bvFTD can live many years with the disease. Research suggests that a person with bvFTD may live an average of six years with the disease, although this can vary from person to person.

Are There Medicines to Treat bvFTD?

Though there is no cure for bvFTD yet, there are medications that may help manage the symptoms. These medications are called *selective serotonin reuptake inhibitors* (SSRIs), and they can help a person with bvFTD manage symptoms of agitation, irritability and lack of motivation.

What Other Things Help?

In addition to medications, there are various ways to help a person with bvFTD. Research has shown that physical exercise helps to enhance brain health and improves mood and general fitness. A balanced diet, enough sleep and limited alcohol intake are other important ways to promote good brain health. Other illnesses that affect the brain, such as diabetes, high blood pressure and high cholesterol, should also be treated if present.

Resources

- [The Association for Frontotemporal Degeneration](#)
- [The Frontotemporal Dementia Support Group](#)
- [Frontotemporal Dementia Caregiver Support Center](#)
- [The Bluefield Project for Frontotemporal Research](#)
- [Alzheimer's Association](#)
- [Family Caregiver Alliance](#)
- [National Institutes of Health](#)
- [Diagnostic criteria for behavioral variant frontotemporal dementia](#)