A Patient’s Guide to Behavioral Variant Frontotemporal Dementia (bvFTD)

This material is provided by UCSF Weill Institute for Neurosciences as an educational resource for patients.
What is dementia?
When medical professionals use the term “dementia,” it refers to a brain problem that makes it difficult for a person to complete daily tasks without help. Symptoms of dementia vary from person to person and may include memory problems, mood changes, or difficulty walking, speaking, or finding your way. There are many different causes of dementia; behavioral variant frontotemporal dementia is one of them.

What is behavioral variant frontotemporal dementia?
Frontotemporal dementia (FTD) is a condition that slowly damages the front or temporal part of the brain. Behavioral variant frontotemporal dementia (bvFTD) is one subtype of that condition. People with bvFTD often have trouble controlling their behavior and judgement. They may say inappropriate things or ignore other peoples’ feelings. People may become more passive or lose interest in things they used to enjoy. 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. Behavior changes may include saying or doing inappropriate things in social settings, lack of motivation, increased frustration, repeating sounds or movements, shoplifting, impulsively buying things, overeating, or forgetting to bathe.

Thinking problems may cause changes such as trouble focusing, paying attention, planning, making decisions, or understanding conversations. Sometimes, people with bvFTD may have weakness in their muscles, difficulty swallowing, or difficulty walking.

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: theaftd.org
The Frontotemporal Dementia Support Group: ftdsg.org
Frontotemporal Dementia Caregiver Support Center: ftdsupport.com
The Bluefield Project/Consortium for Frontotemporal Research (CFR): bluefieldproject.org
Family Caregiver Alliance: caregiver.org
National Institutes of Health: nih.gov
Research: clinicaltrials.gov