Currently, about 300,000 Australians are living with dementia, and this number is predicted to triple by 2050. While dementia is usually thought of as a disease that affects people in old age, at least 5% of people are diagnosed with dementia before they reach age 65. Currently approximately 25,000 Australians under the age of 65 have dementia.

The symptoms of dementia vary greatly, depending on the type of dementia and which part of the brain is affected. Usually, when people imagine someone with dementia they think of someone who has poor memory, difficulty recognising people, and often gets lost or appears confused. While these symptoms are typical in Alzheimer’s disease, the most common type of dementia affecting people over age 65, in younger-onset dementia (before 65 years) the symptoms can be quite different. In this younger age bracket, frontotemporal dementia is as common as Alzheimer’s disease. Unlike Alzheimer’s disease, frontotemporal dementia is associated with changes in behaviour and language.

Frontotemporal dementia causes shrinkage of the frontal and temporal lobes of the brain (see figure). These parts of the brain are crucial for personality and behaviour (frontal lobe) and language (temporal lobe). Frontotemporal dementia is therefore divided into two broad subtypes: 1. **behavioural-variant frontotemporal dementia**, which results in changes in behaviour and personality due to shrinkage of the frontal lobe of the brain and; 2. **primary progressive aphasia**, which results in difficulty with language due to shrinkage of the temporal lobe of the brain.

**What are the symptoms of behavioural-variant frontotemporal dementia?**

Behavioural-variant frontotemporal dementia (bvFTD) can lead to a variety of symptoms. Individuals with bvFTD may have some or all of the symptoms described below [1].

1. **Behavioural disinhibition**

Behavioural disinhibition is an increase in inappropriate behaviour. Individuals may show a loss of manners (e.g., interrupting conversations, talking about inappropriate topics). In some cases, individuals may show inappropriate sexual behaviour, for example making unwanted advances towards strangers, or making sexually explicit jokes. In addition, individuals may be rash or careless in their actions (e.g., gambling, stealing).
2. Apathy

Apathy is a loss of motivation or interest in doing things. Individuals may become more passive and lose their “get up and go”. They may require prompting to participate in social activities or to engage with others.

3. Loss of empathy

This refers to a loss in the ability to understand how other people are feeling. Individuals may be less responsive towards other people’s feelings or needs. They may also lose interest in other people or show less warmth towards others. Some individuals also lose their ability to sympathise with other people.

4. Perseverative behaviour

This is the tendency to continuously repeat the same behaviours. The behaviours can range from very simple behaviours (e.g., tapping, scratching), or be more complex ritual-like behaviours. For example, individuals may develop cleaning rituals or watch the same television program repeatedly. Some individuals also show repetitive speech or develop “catch phrases”.

5. Dietary changes

Up to 60% of patients develop changes in their diet and eating habits. This includes binge eating, increased carbohydrate and sugar preferences, but also can include increased rigidity in the types of foods they eat and often eating the same food repeatedly. Patients can also develop swallowing problems and a marked decline in their table manners. These changes can effect patients’ weight and metabolism, which may impact on disease progression.

6. Problems with planning and reasoning (executive functioning)

Along with these behavioural changes, individuals can show problems with complex thinking, for example planning or reasoning. This can be assessed using neuropsychological tests. Difficulties in complex thinking tend to outweigh problems with memory or visual abilities.

Diagnosis of behavioural-variant frontotemporal dementia

Diagnosis of bvFTD relies on a combination of evidence including: brain scans (e.g., MRI, PET), assessment by a neurologist and neuropsychological assessment. These are important to rule out other potential causes of changes in behaviour and cognition. Because the behavioural changes are difficult to measure, recent research has focussed on developing new tests to assess changes in behaviour, empathy and social skills [2-4]. These can help to assist in the diagnosis of bvFTD.

Impact on carers and their families

bvFTD has significant impact on patients and their carers. Many patients develop symptoms aged less than 65 years and are still working and have teenage children placing significant stress on the family. Many of the behavioural changes including dietary and sexual inappropriateness are difficult to manage and cause significant carer distress. Further, the impact on carer burden increases as the disease progresses [5]. Patients lack
insight into their behaviour and often develop changes in their empathy towards family members adding significant stress [6].

**Treat**ment of behavioural-variant frontotemporal dementia

Currently there are no treatments for frontotemporal dementia. Treatment options have been made difficult due to the challenges of accurate diagnosis and the heterogeneity of the disease.

Current treatment options include the use of psychotropic medications (eg. antidepressants) to control behaviour and supportive treatment for patients and their families. Research is ongoing into the causes and pathology of the disease process and symptoms, which will be important in order to discover new treatment options.

**More information:**

- FRONTIER younger-onset dementia research clinic  
- Alzheimer’s Australia  
- The Australian Fronto-Temporal Dementia Association (AFTDA)  
- Neuroscience Research Australia  

**References:**


