

Behavioural Variant Frontotemporal dementia (FTD) (formerly known as Pick's Disease)

Frontotemporal dementia (FTD) is a complex progressive condition of the brain primarily affecting behaviour, personality and language. FTD occurs less often than other types of dementia e.g. Alzheimer's disease or vascular dementia. It is generally diagnosed in people between the ages of 45 and 65 and affects women and men equally. Because the illness occurs mainly in younger people, issues around employment and dependants are often significant.

Like the word dementia itself, FTD is a term that covers more than one type of dementia: behavioural variant FTD (formerly called Pick's disease), Semantic dementia, Progressive non-fluent aphasia and Logopaenic aphasia. This factsheet focuses on behavioural variant FTD (bvFTD). (See separate factsheets for Semantic dementia and Progressive non-fluent aphasia). Changes in the person are caused by damage to different areas of the frontal and temporal lobes of the brain. These changes may be subtle and go unnoticed at first; however they do progress over a period of years. Behaviour variant FTD is diagnosed in about two thirds of people with FTD and is characterised by changes in personality and behaviour.

Changes that might happen

A person may:

- become less inhibited in their behaviour, e.g. they may make inappropriate comments about someone's appearance or act in an impulsive manner
- demonstrate compulsive or repetitive behaviours, e.g. be obsessed with time or have certain behaviours or rituals that have to be carried out
- experience cravings for sweet foods, cigarettes, fatty foods etc
- may become apathetic and lack motivation, but not be depressed
- lose the ability to empathise with others and this can appear uncaring, cold or selfish.

It is rare for people with early stage behaviour variant FTD to have memory problems or difficulty with judging distance between objects (spatial awareness).

Instead early signs may include problems with planning and organising or money matters and these often come to light in the work environment. The person can lack insight from an early stage, along with a lack of control over their behaviour – and it is often those closest to them who notice the changes.

Things to consider and strategies to cope

Although there is no cure for this illness, strategies can be used to help people cope with changes they experience.

Dealing with behaviour changes can be challenging if you are a carer and/or family member. Sometimes it may be easier to let the person carry on with the behaviour than try to prevent it. Removing triggers, avoiding certain situations or even distracting the person can help.

For example, food cravings or compulsive eating can often be managed by portion control (e.g., offering one or two biscuits rather than leaving out the whole packet, or eating only at mealtimes).

Sometimes, people will display behaviours such as restlessness, agitation and anger – often in response to an unmet need, a sense of frustration or if they are in pain. It is helpful to be sensitive to these possibilities and it's always preferable to manage them without drugs.

It's important that the person remains stimulated and has things to do. Research suggests that when people who are living with dementia become bored, there is a higher chance they will be affected by depression, anxiety, agitation and experience other symptoms such as hallucinations and delirium. Maintaining a routine and ensuring they have the opportunity to be active can help minimise feelings of restlessness and frustration.

Currently, there are no drugs available to treat FTD although there have been some small trials using Alzheimer's disease drugs. These have had mixed results and such drugs remain unlicensed for use with people living with FTD.

Useful information

For more information, please visit **raredementiasupport.org**. Here you will find contact details for support groups which offer advice and information to people living with FTD, their families and carers.

Alternatively, you can call **020 3328 0243** and leave a message for someone to get back to you.

Further information can also be found at **ftdtalk.org**