

Behaviour 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, for example 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). Other early signs may include problems in 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 and can lack control over their behaviour and often it is those closest to the person who notices a change.

¹Scottish Government, The Scottish Health Survey, 2015 Edition, Volume 1, A National Statistics Publication for Scotland, October 2016.

Things to consider and strategies to cope

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

Dealing with behaviour changes can be challenging for the carer/ 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 if they behave inappropriately in public. An example of this is outlined below:

- food cravings or compulsive eating can sometimes be managed by portion control (e.g. putting out one or two biscuits rather than a whole packet) or eating only at mealtimes.

It is always preferable to manage behaviours such as restlessness, agitation or anger without drugs. Sometimes people will display these behaviours in response to an unmet need, a sense of frustration or even if they are in pain and so it is helpful to be sensitive to this possibility. Having things to do is also useful. Routines and the opportunity to be active can all help the person relieve some of the feelings of restlessness and frustration. Currently, there are no drugs available to treat FTD. There have been some small trials using Alzheimer's drugs in people with FTD. These have had mixed results and such drugs remain unlicensed for use with people with FTD.

Useful information

Frontotemporal Dementia Support Group (formerly Pick's Disease Support Group)
Web site www.ftdsg.org
Telephone 07592 540 555 Email jill.walton@ftdsg.org



Alzheimer Scotland
160 Dundee Street
Edinburgh EH11 1DQ
Email: info@alzscot.org
Tel: 0131 243 1453
www.alzscot.org

Alzheimer Scotland – Action on Dementia is a company limited by guarantee, registered in Scotland 149069. Registered office: 160 Dundee Street, Edinburgh EH11 1DQ. It is recognised as a charity by the Office of the Scottish Charity Regulator, no. SC022315