



## Frontotemporal Dementia Support Group

(formerly Pick's Disease Support Group)

FTD SUPPORT GROUP  
FTDSG

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### Regional Contacts:

**Yorkshire** – Rev. Ronald Carter 01904 610 237

**Northern** – Mrs Jillian Ramsay 0191 421 4069  
mob; 0770 885 7438

**Trent** – Mrs Janet Carpenter 0116 239 2913  
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**Mersey and North West** – Mrs Mary Dawber 01625 879 104  
Email [mary1246@hotmail.co.uk](mailto:mary1246@hotmail.co.uk)

**West Midlands** – Sister Ann Johnson 01743 492 175

**Central** - Mrs Sue Smith [YoungDementia UK]  
01235 522 382 [ Mon-Thursday 9am-5pm]

**Northamptonshire:** Rob Hasker  
Email by preference [robert.hasker1985@hotmail.com](mailto:robert.hasker1985@hotmail.com)  
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**London** – Mrs Carole Ivey 0207 603 0550

**Southern [Hants. Wilts.]** – Mrs Jenny Mackie 01722 336 352

**Southern [Surrey Sussex]** – Mrs Val Bywater 01420 362 123  
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**Suffolk** - Mrs Gillian Gubb 01502 569077

**South West** – Miss Penelope Roques 01297 445 488

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### Incorporating:

**Behavioural Variant Frontotemporal Dementia (including Pick's Disease)**

**Primary Progressive Aphasia**

Progressive Non-Fluent Aphasia

Semantic Dementia

Logopenic Aphasia

**Alcohol Related Dementias**

Having dementia brings problems enough for both those with the disease and their carers. When it affects younger people and when the form of dementia is rare, then the problems that have to be faced are even more complex. Getting a correct diagnosis may be difficult. Few facilities are appropriate to this group's specific need. Carers find it hard to plan for the future and may feel very isolated.

The Frontotemporal Dementia Support Group [ formerly Pick's Disease Support Group ] was formed:

To decrease the sense of isolation felt by carers

To facilitate a sharing of problems, feelings and ideas

To give both those with the disease and their carers up to date information on the rarer dementias.

**The FTDSG covers a range of illnesses that cause dementia, particularly where there may be behavioural problems, and seeks to raise awareness of Frontotemporal dementia.**

The FTDSG is under the umbrella of The National Brain Appeal [ formerly National Hospital for Neurology and Neurosurgery Development Foundation], registered charity number 290173.

If you would like to receive literature from the FTDSG please complete your details and return to: **Jill Walton, 22 Brushwood Drive, Chorleywood, Herts WD3 5RT**

We will send you an information pack and add your name to our database of members. This information is solely for FTDSG purposes.

Visit us at [www.ftdsg.org](http://www.ftdsg.org) for more information and to access meeting dates.

Contact your local Regional Contact Person or one of the advisers for more information.

Regional contact people are volunteers, and have either professional or personal experience of the disease.

NAME.....

ADDRESS.....

COUNTY.....

POSTCODE.....

TELEPHONE.....

EMAIL ADDRESS.....



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### Frontotemporal dementia [including Picks Disease]:

Frontotemporal dementia (FTD) (sometimes called frontotemporal lobar degeneration, FTLD) is a group of conditions caused by loss of cells mainly in the frontal and temporal lobes of the brain. The main symptoms are a progressive change in personality or behaviour **and/or** progressive deterioration in language abilities. It can affect both men and women and usually starts in the 40's, 50's or 60's. However it can also affect older people, and very rarely even younger people. It was originally described by Arnold Pick in 1892 after whom it was named. Most doctors now prefer to reserve the name '**Pick's disease**' for just one of the types of changes in the brain tissue that may be seen with the disease.

The group supports carers of people with of frontotemporal dementia. FTD is classically subdivided thus:

#### 1. Behavioural Variant (bvFTD)

Behavioural variant (bvFTD) is caused by loss of brain cells mainly affecting the frontal and temporal lobes of the brain. These areas control behaviour, personality and complex thinking such as planning or problem-solving.

#### 2. Primary Progressive Aphasia

PPA is caused by degeneration (loss) of brain cells mainly affecting the parts of the brain (the frontal and temporal lobes on the left side) that control speech. It constitutes a group of disorders in which people develop progressive loss of their language abilities and includes:

Progressive Non- Fluent Aphasia  
Semantic dementia  
Logopenic Aphasia

### Alcohol Related Dementias

Chronic excessive alcohol use can damage the brain in one of three ways. First, there is an acute disorder in which confusion is combined with neurological symptoms; this can be life-threatening and is called *Wernicke's encephalopathy*. Then, after recovery from Wernicke's, there often follows a chronic memory deficit, known as *Korsakoff psychosis*. Lastly, a more generalised *dementia* may arise with an emphasis on memory disorder and **problems with behavioural regulation**. In surveys of younger people with dementia causes due to alcohol account for at least 10% of cases.

There are other dementias that can affect behaviour and thinking:

**Cortico basal degeneration** is the name given to a progressive degenerative disorder causing problems with movement and thinking. The disease is named after the parts of the brain affected– cortico refers to the cortex, which is the outer layer of the brain, and basal refers to the basal ganglia which are the structures deep in the brain that control motor skills. For more information about this disease please visit [pspeur.org](http://pspeur.org)

**Dementia with Lewy bodies [DLB]** is caused, like other dementias, by an accumulation of abnormal proteins within the brain. In DLB, the abnormal protein is 'alpha-synuclein', and this is what is found in the 'Lewy bodies' that are seen under the microscope in the brains of people with DLB at post mortem. For more information please visit: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

#### SYMPTOMS TYPICAL OF THESE ILLNESSES

**Personality change:** loss of inhibition, obsessive behaviour, withdrawal

**Lack of insight into illness**

**Changes in social behaviour**

**Stereotypical Behaviour:** wanting to stick to strict routines

**Gluttony:** overeating and changes in dietary habits

**Speech Problems:** loss of quantity and quality of speech [sometimes total loss of speech], difficulty finding words, problems swallowing

**Movement problems, rigidity and stiffness**

**Memory Problems**

**Visual Disorientation**

## ELAINE'S STORY

It is now four years since my husband Tom started showing signs of his illness. He was 55. At first I thought his indifference towards me was due to business worries...then I learned that this is often a part of this disease. During those four years we have both suffered despair and anger...but have also had a lot of laughter.

It took two years to get a diagnosis. It turned out to be Pick's Disease. Tom couldn't understand what was happening to him. He used to say "Elaine, I'm so frightened. I don't know what's wrong with me. Please help me". I felt so inadequate. His understanding of what words meant was affected. He spent hours every day reading the dictionary and repeating and spelling words back to me. Keeping him well and getting him to do the things we enjoyed together, like walking and swimming, seemed to help.

Two years into the illness, his frustration became more noticeable and he became stubborn and aggressive. Life was a constant battle - I felt that I was walking on eggshells. He became very rude and sometimes tried to head butt people when we were out shopping. Thankfully the doctors prescribed drugs that helped him to be calmer. The hardest part for me is the loneliness - I miss the Tom I had known for so long and it is difficult to find people who really understand what it is like for us.

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