

frontotemporal dementia



[FTDSG] SUPPORT GROUP

(formerly *Pick's Disease Support Group*)

www.ftdsg.org

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 list of members which is solely for FTDSG purposes.

For more information and to access meeting dates:

www.ftdsg.org

Contact your local Regional Contact Person for more information about local provision where possible .

Regional contact people are volunteers with either professional or personal experience of the disease.

NAME.....

ADDRESS.....

COUNTY and POSTCODE.....

TELEPHONE.....

For general support group enquiries contact
Jill Walton, Group Coordinator

Tel: 07592 540 555 email: jill.walton@ucl.ac.uk

For funding enquiries contact
**Lynne Ramsay, Volunteer Funding and Services
Adviser**

Tel: 0208 467 1462 Mob: 07760 224 396

Regional Contacts:

Scotland—Anne Miller 01436268476
milleranne89@googlemail.com

Yorkshire – Rev. Ronald Carter 01904 610 237
Anne Squires 0113 2947139

Northern – Mrs Jillian Ramsay 0191 421 4069
m0770 885 438

Manchester/ Stockport—Helen Griffiths
helen.griffiths@nhs.net 0161 716 4505

Mersey and North West – Mrs Mary Dawber
01625 879 104
Email mary1246@hotmail.co.uk

West Midlands – Sister Ann Johnson 01743 255856

Birmingham— Pauline Ross 07815285876
polly.ross@btopenworld.com

Kirsty O'Dwyer 07887800947
kross38@hotmail.com

Kirsty is happy to take calls from anyone whose parent is affected by FTD

Central - Emeline Keown [YoungDementia UK]
01865 747698 Mob: 07909 060430
emelinekeown@youngdementiauk.org

Northamptonshire— Hilda Hayo 07920 819523
hhayo@talk21.com

London – Mrs Carole Ivey 0207 603 0550

Cambs— Val Freestone 01223 768005
valerie.freestone@addenbrookes.nhs.uk

Herts/Beds—Richard Pleydell-Bouverie 01438 833022
richard@lawrenceend.com

Kent/Sussex– Jane Smissen Bell 01323 504156
6bells.jane@gmail.com

West Sussex– Jill Butcher 01444 451 837
jillbutcher@onetel.com

Suffolk - Mrs Gillian Gubb 01502 569077

Norfolk—Gillian Litson 01263 514624

South West – Miss Penelope Roques 01297 445 488

Cornwall—Mrs Cindy Reeve 01726 71562

South Wales – Mrs Pat Coulson 01792 883 684

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Incorporating:

Behavioural Variant Frontotemporal

Dementia (including Pick's Disease)

Primary Progressive Aphasia

Progressive Non-Fluent Aphasia

Semantic Dementia

Logopenic Aphasia

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 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 these rarer dementias.

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

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Frontotemporal dementia [including Pick's 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 provides support group meetings, newsletters, telephone contact networks, websites and access to information for carers of people with 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)

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

For more information about the PPA support group please visit <https://www.ucl.ac.uk/drc/support-groups/PPA-support-group>

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

Other sites of interest include:

Familial Frontotemporal Dementia Support Group (fFTD) –
www.ucl.ac.uk/drc/support-groups/fFTD-support-group

For people affected by the rare autosomal dominantly inherited frontotemporal dementia

www.pspassociation.org.uk For people affected by PSP and CBD diagnoses

www.ftdtalk.org This site provides jargon free research updates on FTD for all people in the FTD community.

www.theaftd.org This American site hosts a wealth of resources which they are happy to share.

www.ecdc.org.au This Australian site has produced a toolkit which addresses many of the issues that present as a result of a diagnosis of FTD.

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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