

FTD support group small group discussion - Regional Support

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The information in this document reflects the content talked about at the FTD small group discussion at this Rare Dementia Support meeting. Please note the suggestions discussed are not intended to be used as a prescriptive list as people's experiences of dementia vary hugely - people may or may not find the information helpful. You assume full responsibility and risk in the use of information contained at support group meetings and in subsequent correspondence. We aim to ensure that all information is as accurate as possible, but we accept no responsibility for any errors, omissions or inaccuracies, or for any adverse consequences of any kind arising from the use of support group based content. Any organisations or products mentioned at the support group meetings do not reflect all those available and any clinical queries answered at our support groups should be taken as advice only. Any medical decisions should be taken in discussion with an appropriate health care professional.

Regional Groups

- Variations between different groups; some more formal with speakers, and some very informal catch-ups in cafes etc. Will sometimes just have individuals with a particular diagnosis that would like to link up with another individual with the same diagnosis for a chat- Roberta can help to facilitate this between members.
- A handbook is currently being developed which will include clear guidance on the regional support group structure, which will assist those who want to set up their own groups.
- There are about 25 groups across the UK; however, there are a number of areas that are not covered e.g. Wales.
- Additionally, there are some members that offer telephone and/or email support
- To find regional groups: go to <http://www.raredementiasupport.org> , go to groups and select the type of dementia, scroll down and there will be a section on meetings, select 'regional'. Some contacts are not listed on the website, so if you have any queries about groups local to you, then please contact Roberta directly on r.mckee-jackson@ucl.ac.uk.

Mapping Project

- Have started mapping the general location of support group members to help match people up (with their consent). Have also added the regional support group locations to this map, which will eventually be accessible to the public via the website.

Other Organisations and Activities (mentioned in the small group discussion)

- **Young Dementia UK** have a number of support groups across the UK. They also have a section on their website with information about local support groups/organisations: <https://www.youngdementiauk.org/support-across-uk>
- **Alzheimer's Society** services vary from region to region. A lot of their services, such as day centres and memory cafes, may be more catered to older people with memory impairments, so may not be suitable for people living with FTD
- **Dementia Engagement and Empowerment Project (DEEP)**: over 100 groups of people living with dementia. List of groups can be found on their website here: <https://www.dementiavoices.org.uk/a-z-list-of-groups/>
- **Dementia Carers Count**: free 3 day course for carers: <https://dementiacarers.org.uk/get-support/dementia-carer-support-courses/>
- **Dementia Wellbeing Service (Bristol)**: support for people living in the Bristol area <http://www.bristoldementiawellbeing.org/>
- **Men's Shed**: social activity for men (not specifically for people living with dementia), locations all around the UK (<https://menssheds.org.uk/>).
- **Ugly Duckling**: furniture upcycling in Hampshire (<http://www.ugly-duckling.info/>).

For information on support groups local to you, please contact Roberta McKee- Jackson:

r.mckee-jackson@ucl.ac.uk.