

## **FTD support group small group discussion - Activities to do with someone living with FTD**

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**Scribe:** Hannah Carr

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.

Nikki facilitated this small group to discuss what activities you can possibly do with someone living with FTD. Nikki wanted to state that just because someone has FTD does not mean that they need to do specific activities related to their condition. They are still a person and we should take a more person centred approach to activities. For example, what do they enjoy or what did they enjoy? What was their occupation? All of these things can help suggest what activities the person may be more inclined to take part in and actually enjoy!

It's all about trial and error – there may be something that they enjoyed before but do not like anymore and vice versa so it's about trying everything until you find the right thing.

There are many activities out there to do and many organisations that run activities for those living with dementia, not specifically those living with FTD. This document will cover some but will not be an exhaustive list of all activities, organisations and products that can be used. Attached is a document on art based activities that those from **St George's Young Onset Group** have been involved in and have enjoyed (please note that these are London based).

Other activities that Nikki mentioned **based in London** are as follows:

- **Singing for the Mind:** Singing for the Mind enhances social activity and brings fun and confidence to lives affected by memory problems. Through music, people share a joy of creating, learning new songs and rekindling memories through old favourites. These sessions can give people with dementia and their carers a more positive view on life. Sessions are run by a singing leader together with specially trained volunteers. The aim is to reduce social isolation by creating an environment for friendship, enjoyment and mutual aid.

Contact telephone 020 7286 5181 Contact email [sfm@ljs.org](mailto:sfm@ljs.org)

- **Millman Street Community Centre:** Community Centre that offers a range of activities and support services for people over 55. The programme includes:

reminiscence, arts and crafts, seated exercise, gardening, singing, tai chi, yoga, computer, play, reading, live concerts, outings (e.g. visits to museums) etc. When possible, activities are inclusive to all members but some small group activities are targeted to meet the needs of people with moderate dementia; people aged 55 and above, including people with moderate dementia

Contact telephone 020 7405 2493

Contact email [richard.norman@holborncommunity.co.uk](mailto:richard.norman@holborncommunity.co.uk)

Service web site [www.holborncommunity.co.uk](http://www.holborncommunity.co.uk)

- **Haringey Support Group:** A self-organised support group for people with young onset dementia and their carers on the fourth Friday of the month. In addition, there are monthly group CST sessions for group members with dementia. Group members participate in a variety of dementia friendly activities, including yoga, dance therapy, cycling, creative arts, nature walks and theatre projects and go out for regular support group meals.  
Email: [rosedep@blueyonder.co.uk](mailto:rosedep@blueyonder.co.uk)
- **St George's Young Onset Support Group:** Each support group meeting includes a talk or presentation, plenty of time for questions and time to meet other people who are living with early onset dementia and their families. The meetings are held at St George's Hospital John Parker Lecture Theatre on the last Wednesday of each month. There are disabled friendly facilities and refreshments provided.  
Email: [nikki@cog-neuro-support.com](mailto:nikki@cog-neuro-support.com)
- **Songhaven:** Enjoy a 45minute dementia-friendly music concert in one of London's most beautiful Victorian churches, followed by a social afternoon tea. The programme will feature favourite melodies from the operatic stage, tunes from the classic musicals, and well-loved songs from the past, performed by three professional artists.  
Website: <http://songhaven.co.uk/>
- **Royal Academy of Arts:** InMind is our programme of art sessions for visitors living with early to mid-stages of dementia and their carer's, friends and family members. Each session is facilitated by artists and gallery educators and allows participants to choose between a discussion session focused on an artwork from the RA Collection or an art-making workshop.  
Website: <https://www.royalacademy.org.uk/access-at-the-ra>
- **Cinema – Phoenix Cinema:** Our Cinememories dementia friendly screenings are free for anyone over 60 and two guests of any age, such as friends, family or carers. The screenings will be shown with brighter lighting, quieter sound and an interval in the middle of the film for a sing-a-long and comfort break. The screenings also include free coffee, tea, popcorn and biscuits. A Dementia Adviser for the borough of Barnet (representing the Alzheimer's Society) will be present at the screenings, offering information on how to live well with dementia and the support available for carers for someone living with the condition.  
<http://phoenixcinema.co.uk/PhoenixCinema.dll/Page?PageID=0&SubListID=3&SubPageID=0>

- **Dementia Friendly Theatres:** The Prince Edward Theatre is owned by Sir Cameron Mackintosh and operates as one of the seven most prestigious theatres of Delfont Mackintosh Theatres Ltd in London's West End. All seven theatres have first class access facilities and are now looking at providing a fully accessible dementia friendly theatre experience.

Website: [www.delfontmackintosh.co.uk](http://www.delfontmackintosh.co.uk)

- **The Royal Academy of Music** <http://www.ram.ac.uk/>
- **Westminster Arts:** They work with a wide range of artists and other partner agencies in Westminster and across other London boroughs, focusing on the needs of socially isolated and vulnerable members of our community.

Website: [www.westminsterarts.org.uk](http://www.westminsterarts.org.uk)

More details can be found for Dementia Friendly services in Westminster at [http://www.dementiaaction.org.uk/local\\_alliances/3628\\_westminster\\_dementia\\_action\\_alliance](http://www.dementiaaction.org.uk/local_alliances/3628_westminster_dementia_action_alliance)

- **Dance for Dementia:** Free, specialised dance sessions to energise people in the early stages of dementia. Companions, friends, family members and carers also welcome. Each workshop comprises of warm-ups, partner and group exercises, dance and a chance to explore steps from Rambert's repertoire to stimulate movement memory. There are also opportunities to interact with other participants, to observe Rambert's dancers in open rehearsals, and to explore the company's history in the archive. There's also tea and biscuits. Participation is free.

Venue: Rambert, 99 Upper Ground, London SE1 9PP

For more information or to enrol, contact Katie Mason, Elders Programme Co-ordinator

Tel: 020 86300615

Email: [katie.mason@rambert.org.uk](mailto:katie.mason@rambert.org.uk)

- **Healthy Walks at Kew Garden;** Relaxing walks through Kew are for people living with dementia and their carer's. The walks are led by Kew's volunteer walk leaders and take place on the third Tuesday of each month (except January) at 10.30am. Each walk lasts about an hour and sets out from the Victoria Gate. These walks are free, and free entry to the Gardens is included. Places are limited so please register in advance to avoid disappointment.

Website: <https://www.kew.org/kew-gardens/whats-on/health-walks-for-people-living-with-dementia>

- **Sensory Palaces;** Sensory Palaces is a health and wellbeing programme, managed by the Learning & Engagement team at Historic Royal Palaces, for people living with early stage dementia and their carer's. The programme, currently based at Hampton Court Palace, engages audiences in the palaces through a unique combination of senses, spaces and stories.

Website: <https://www.hrp.org.uk/hampton-court-palace/#gs.muibyb>

We understand that not all members are based in London and will require activities that are more local to them. We then discussed activities and organisations based around the UK.

A few members of staff from the **Younger People with Dementia Berkshire** were in the discussion group and spoke about the activities they do for those living with a dementia under 65 including those with FTD. They have 13 workshops a week covering a range of activities from equine therapy, a choir and cata-canoeing. These activities are free for those within Berkshire and £5 for those living outside of Berkshire. A link to their website is here: <http://www.ypwd.info/>

There seems to be a lot of art based activities available and one member asked how they could start up their own dementia choir. Tips from others in the group were to start small with maybe one musician to help and approaching other choirs for advice or possible collaborations.

**Other activities that members suggested were:**

- Magic tables; these are projections onto a table and provide a range of activities that can be done as a group or individually. These have been used by members in libraries in Hillingdon. More information on these magic tables can be seen here <https://tovertafel.co.uk/care-innovation-dementia/>
- Bead/jewellery making
- Dominos
- Playing cards
- Colouring books – some members spoke about more cognitively stimulating colouring books that ask you to match the colours to those already shown etc. These are available from multiple organisations and can be found by searching for dementia colouring books
- Knitting – activities that focus on repetitive behaviours can be useful for those with FTD and some members spoke about muscle memory and how some of their loved ones living with FTD were able to continue to knit even though other abilities may have become impaired
- Word searches – members spoke about family members living with FTD still enjoying a word search. Sometimes they will not complete it in the conventional way but if they are enjoying it they let them continue as they are.
- Gym; some gyms will offer a discounted membership for those living with dementia and some may also have dementia friendly classes. Enquire at your local gym.

During the discussion some member's mentioned that their partners are now unable to attend certain activities such as art classes due to their symptoms. We want to highlight the value of volunteers, befrienders and side by side buddies. These people can help encourage activities that those living with dementia may not have thought about doing or assist them to continue doing the activities they enjoy but can no longer do on their own.

Some organisations that do this include Age UK (<https://www.ageuk.org.uk/camden/our-services/dementia-support/dementia-befriending/>) and Alzheimer's Society (<https://www.alzheimers.org.uk/get-support/your-support-services/side-by-side>)

### **Cinema - CEA Card**

The CEA Card is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA) for those receiving Attendance Allowance (AA) or Personal Independence Payment (PIP).

The Card enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema. The Card is also one way for cinemas to make sure they look after their disabled guests. If you require an adjustment to visit a cinema because of your disability, cinema staff should make them for you whether you have a CEA Card or not.

The CEA Card is accepted at approximately 90% of cinemas in the UK.

More information can be found on their website <https://www.ceacard.co.uk/>

### **Animals**

Members spoke about the use of animals to provide companionship for those living with FTD. Equine therapy was previously discussed by staff from Younger People with Dementia Berkshire but other members spoke about dogs. One member suggested using websites where you can borrow a dog for the day such as <https://www.borrowmydoggy.com/>. Members said this can be nice as you can take the dog for a walk and spend the day without the full commitment of owning a dog.

Others also suggested Alpaca therapy and said how this has been quite useful. There are a few Alpaca therapy centres around the UK including in North Yorkshire (<https://www.nidderdalellamas.org/parties-and-services/llama-therapy/>) and some centres have also gone out to care homes with their Alpacas!

### **Going Abroad**

Some of our members spoke about going abroad as a main activity still. To assist in going abroad, some airports will provide assistance for those living with dementia. If at least 48 hours' notice is provided to the airport and airline, fast track services, assistance on and off of the plane and even providing seats closer to the exit can be provided. Members spoke about using this at Heathrow ([https://www.heathrow.com/file\\_source/Heathrow/Static/PDF/Airport\\_guide/dementia-passenger-leaflets.pdf](https://www.heathrow.com/file_source/Heathrow/Static/PDF/Airport_guide/dementia-passenger-leaflets.pdf)) but check with other airports as they may do something very similar.

### **Transport**

To get to many activities people will need to use public transport. TFL now provide dementia assistance on and off of trains and buses.

As of 30<sup>th</sup> August 2019, all those diagnosed with dementia will be eligible for a blue badge. This will make parking a lot easier for those with dementia including FTD and can help make it easier to attend a variety of activities.

Nikki finished the session with some tips on some organisations to look out for that may have some useful dementia friendly activities in local areas:

- Dementia friendly communities (<https://www.dementiafriends.org.uk/WebArticle?page=dfc-public-listing#.XSMUfutKiU>)
- Dementia Action Alliance (<https://nationaldementiaaction.org.uk/>)
- Young Dementia UK (<https://www.youngdementiauk.org/support-across-uk>)
- Alzheimer's society (<https://www.alzheimers.org.uk/find-support-near-you>)