



RARE DEMENTIA SUPPORT

FTD Support Group Newsletter - December 2016

www.raredementiasupport.org

FTD Support Group Newsletter

Welcome to the December 2016 edition of the FTD Support Group newsletter. We are currently trialling various different formats for the newsletter, and welcome your feedback on an ongoing basis. Recordings of presentations given at support group events are regularly uploaded onto our website too and can be accessed via the website www.raredementiasupport.org. The summer has seen us say goodbye to Tim Shakespeare and Amelia Carton, both of whom sent their regards and best wishes to all of you before they left. We are however delighted to be welcoming Rachel Crane to the support group team as a 'Support Group Facilitator and Psychology Research Assistant - Rare Dementia Support', and we look forward to having Rachel alongside us in our ongoing ventures. May we take this opportunity to welcome you to the FTD Support Group meeting on 9th January 2017 (note the new venue details as listed later in this newsletter) and the **Annual FTD Seminar on 2nd March 2017**. We look forward to welcoming you to these meetings, or indeed being in contact with you in whatever capacity is most appropriate.

Rare Dementia Support is part of the collaborative Steering Group for the Young Dementia Network. As such, we are excited to announce the launch of the Young Dementia Network following the Young Onset Dementia Conference in September 2016. Tessa Gutteridge, Chair of the Young Dementia Network Steering Group, said: "We know first-hand the impact of dementia on younger people and their families and how isolating it can be. We believe that everyone affected should be well informed, feel connected to others and enabled to live life to the full. We are creating a Network. A community that includes people living with young onset dementia, their family and friends, as well as organisations and professionals who work in the fields of dementia and social care."

The Young Dementia Network will:

- Provide opportunities for members to share experiences, knowledge and to learn from each other.
- Encourage improved young onset services across the UK and influence and inform national and local policies.

Why join?

Joining the Young Dementia Network is free of charge and whilst there is no obligation to participate in activities and events, there will be lots of opportunities for you to become involved if you wish.

Joining will give you:

- Access to young onset dementia information, guidance and tools
- Regular newsletters including young onset specific information, events and research
- Events around the UK and online
- Opportunities to raise awareness of young onset dementia.

To join the network visit:

www.youngdementiauk.org



Young Dementia
Network

The International FTD Conference, Munich Professor Jason Warren, UCL 31st August - 2nd September 2016



The work of the Dementia Research Centre was recently featured at the 10th International Conference in Frontotemporal Dementias in Munich. This is a major (biennial) conference dedicated to these diseases and helps set the research agenda and clinical practice standards on a global stage. Researchers from the DRC presented a total of 32 papers covering a breadth of topics ranging from cell and tissue pathology to dementia care delivery, and included five invited lectures and chairing of two plenary sessions; Jill Walton was invited to address the Caregiver Symposium, a particularly highly valued component of the conference. The findings from the GenFI cohort (led by UCL) were highlighted as a flagship resource for detecting and tracking disease at the earliest stages in people with genetic mutations and have set a model for exciting parallel consortia involving major US centres. Among the most exciting developments reported were the identification of new spinal fluid markers for assessing disease onset and severity, new MRI signatures of genetic frontotemporal dementias and physiological markers of disease that bring us closer to measuring brain protein malfunction directly. The work of the DRC has helped establish each of these initiatives. Another key theme of the conference was the unification of frontotemporal dementia with motor neuron disease and Parkinson's-like syndromes, setting up shared strategies for understanding disease mechanisms and designing treatments. In the realm of molecular biology, we heard about remarkable recent progress in modifying disease gene and protein activity in model systems with the promise of translating these to human patients in the foreseeable future. We also heard the results of the first human drug trials in frontotemporal dementia; while these have not identified an effective treatment, they represent a tremendous commitment of organisation and collaboration between doctors and scientists and have taught us many lessons that will bear fruit in the selection of new drugs and the planning of larger and more powerful trials in future. There is a real sense of progress at large in the field of frontotemporal dementia and well founded optimism looking forward. Our Centre is at the forefront of the international research effort in frontotemporal dementia thanks to the tremendous support of our patients, families and caregivers who make our work possible.

6th FTD UK Annual Meeting, Cambridge 2016

The 6th Annual meeting of FTD researchers across the UK was held on 4th November 2016 at Wolfson College, University of Cambridge. The meeting was co-ordinated by [Dr Jonathan Rohrer](#) (University College London), [Dr James Rowe](#) (University of Cambridge) and [Prof Stuart Pickering-Brown](#) (University of

Manchester). Among many of the speakers Dr Martina Bocchetta from UCL spoke about imaging of subcortical structures and their connections in FTD. At the close of this very informative day, an update on UK FTD initiatives were discussed.



'Caring for Me and You'

The Alzheimer's Society and psychologists from Oxford Health NHS Foundation Trust have developed an online therapy package designed specifically to support people caring for someone with dementia.

The programme is **suitable for people who are caring for someone with a diagnosis of a dementia and are experiencing mild or moderate levels of anxiety or depression**. Participants also need to be over the age of 18, living in the UK, be comfortable with the English language and have the ability to use a Windows computer with internet access (unfortunately Macs and mobile devices don't work).



More information about this research project can be found at:

<https://www.caringformeandyou.org.uk/>.

Fundraising Updates

Thanks to our recent fundraisers!

Many thanks to everyone who has supported the fund for Rare Dementia Support this year. The service is entirely funded by donations and your fundraising, so it is no exaggeration to say we couldn't do it without you!

Special mentions to...

Richard and Simon Watson and the Longfei Taijiquan Association for raising almost £2,000 in July split between Rare Dementia Support and FTD Research; 10-year old **Lucas Church-Wood** whose grandma has FTD and who took on a mud run this summer; **Lisa Wilkinson** who organised a trifle challenge in memory of her father, Neil Wilkinson; **Laura Harris** whose mother has PPA and who is selling apples to raise FTD awareness; **Chris Hardy** who raised almost £4,000 with the Ironman Wales in September; and finally **Jill Walton and Martin Reeves** who took part in the Royal Parks Foundation Half Marathon in October and between them have raised over £6,000.

David Baddiel, whose father has FTD, also did a special charity performance of his West End show 'My Family: Not the Sitcom' on 23rd September 2016 and a bucket collection for the two final weeks of all performances. £8,285 was raised and is being divided between Rare Dementia Support, Alzheimer's Society and Unforgettable Foundation.

If you are interested in participating in a challenge, organising a fundraising event of your own or making a donation to the fund for Rare Dementia Support, please email louise.knight@uclh.nhs.uk or phone 020 3448 4724.

You can also donate online via JustGiving – go to bit.ly/RDSfund and please share the link with anyone you know who also wants to support the fund.

You can also text RDSF84 followed by the amount you would like to donate to 70070.



The First “Dementia Friendly” Supermarket in Sussex...

Our West Sussex regional facilitator, Jill Butcher and Dawn Fairbrother, Dementia Action Alliance Co-ordinator & Carers Information and Support Programme Facilitator from the Alzheimer's Society recently met their local Sainsbury's Store Manager, Rafe Overy. The meeting was inspired as a result of Jill's husband's experiences of the security staff at the store. At the meeting, the Deputy Manager, HR Manager and four members of the management team were present. Jill talked to them about FTD. Dawn told them about dementia in general and talked about the Dementia Friends initiative. They both provided lots of ideas and issued pamphlets. As a result of their meeting, the Sainsbury's Store Manager said that they are going to work towards being a dementia friendly store (apparently there are no dementia-friendly Sainsbury's branches in Sussex as yet) – this is an excellent outcome – **Well done Jill and Dawn!**

Dementia Friendly Communities is a programme which facilitates the creation of dementia-friendly communities across the UK. Everyone, from governments and health boards to the local corner shop and hairdresser, share part of the responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community.

More information about Dementia Friendly Communities can be found at: <https://www.alzheimers.org.uk/dementiafriendlycommunities>.



‘Dementia Adventures’ Have Changed Our Lives Article

“Dementia changes lives for families, not just individuals” - in this article, Christine Ellis, a carer and FTD support group member reflects on how her family has coped with FTD. She is very transparent from the start; she had never heard of FTD or “Pick’s Disease”, as it used to be known, until her husband was diagnosed with the condition in April 2012. Christine tells of the difficulties she encountered when she tried to explain her husband’s symptoms to his doctor, and her husband’s lack of insight into his condition. She describes how her husband, previously at the top of his profession, is now unable to perform even the simplest task, and has a childlike dependence on others for all of his day-to-day needs. Explaining that her husband is unable to remember the past and the future means nothing to him and that despite his diagnosis he remains happy, Christine comments on how lovely it is to see his reaction to everyday things which we take for granted. Christine reports how much her husband enjoys weekly music therapy sessions and that he is still able to sing many songs in his beautiful Welsh voice. Referring to the fact that FTD is an ‘invisible’ condition, she comments that “the sad side is that he appears fit and well and unless you know him, you would not think that he has such a devastating illness”. She explains that she feels the worst symptoms of FTD are the socially unacceptable and inappropriate behaviours and the ritualistic, constant pacing and restlessness. At the end of the article, Christine mentions how much she misses her husband and she feels that she has “lost the person he was”. As validated by research findings, she concludes that the most difficult aspect is the lack of empathy. The benefit of music therapy for people affected by FTD is highlighted on the following page of this newsletter.

You can access the full article at: <http://www.gloucestershirelive.co.uk/wife-s-touching-account-of-husband-lost-to-dementia/story-29778167-detail/story.htm>.

Music Therapy

This piece leads on from the previous article, "Dementia Adventures". Information has been kindly shared by Christine and David Ellis and his Music Therapist, Jane Crampton.

There is much literature and research that suggests music therapy has positive effects on communication, physiological, cognitive and social aspects within a person who has dementia. Singing in particular encourages social interaction and engagement. It can also have positive effects on stress, agitation, social behavior, language function, periods of lucidity, feelings of identity and reminiscence. The aims of music therapy include:

- To encourage awareness of self, of others and of the environment;
- To provide opportunities for positive interaction and a sense of belonging;
- To offer music as a means of self expression and communication, using both known song and improvisation to encourage forgotten and innate structures;
- To promote self esteem and self worth;
- To decrease isolation, anxiety, confusion or any obsessive behaviours.

David was referred for music therapy by his wife, Christine in 2015. Individual music therapy sessions commenced in November 2015 and have taken place each week at their home with each session lasting for an hour. Various large and small percussion instruments are used during their sessions. The instruments were specifically chosen for their accessibility and ease of playing so that David was able to produce sounds with very little physical effort. As well as these instruments, David's music therapist used a piano. As this approach was 'client centred', David's decision not to actively play or sing was respected, and he was free to leave the room at any time. The sounds and music which David created were supported by his music therapist on either guitar, piano or voice.

At the start of the therapy, Jane reported that she observed David showing signs of some obsessive, possibly anxious behaviours. She also noticed that when she engaged David in eye contact, he would stare at her and repeat short random phrases which were unrelated to the moment. However, when Jane started to sing well known songs, David's response was almost immediate and he became more engaged during his sessions. Jane reports that she encountered some negative verbal responses from David initially but as the session went on David would begin to engage. Jane describes some obsessive and perseverative behaviours when using some of the instruments and difficulties processing the music he was hearing; at times he would play his own repeated rhythms for some time seemingly unaware that Jane had stopped playing. Jane also remarked on David's whistling. As well as using instruments, Jane also incorporated music. She noticed that musical genre seemed to engage, calm and relax David and also helped refrain him from any whistling. Over time, Jane reports a lessening of his ritualistic behaviours and that he now very rarely uses repetitive verbal phrases. Although his whistling is still apparent, it appears much less obsessive. David is now more able to focus and engage for one hour and appears more aware of when the music is slowing down. Jane explains that their social interaction occurs through music. David is able to make his own choices; he is able to engage very positively through the music and is very motivated by this medium. Finally, Jane explains that although it is not possible to treat the primary degenerative symptoms of FTD, it is possible to address the secondary symptoms that are often expressed as repetitive or inappropriate behavior. These can be reduced through participation in a meaningful occupation such as music therapy. There continues to be evidence of this during David's music therapy sessions.

**Special thanks given to Jane Crampton, Music Therapist.
BA Hons; MA (Mus.Th). HPCP Reg: AS00988.**

Interaction-Focussed Life Story Work in Semantic Dementia

By Dr Jackie Kindell, Speech & Language Therapist, Pennine Care NHS Foundation Trust/
Honorary Lecturer, The University of Manchester.

Life story work is an approach where important aspects of an individual's life, memories and identity are recorded and actively used to improve the delivery of person-centred care. For example, life story books, or memory boxes, are made with treasured photographs and memorabilia to enhance interaction. Applying this approach specifically to communication has been termed 'interaction-focussed life story work'. There is, however, a lack of research examining how this approach might be adapted to the needs of those with rarer dementias. In this research project I worked with five families where one family member had a diagnosis of semantic dementia (one of the language variants of FTD), visiting participants over a period of 18 months (8-20 visits per family). This helped me to gain an in-depth insight into the issues that they were facing with communication. I used a small camcorder to video everyday conversation at home and carried out a number of interviews to help provide context. Following this assessment I worked with the family and the person with semantic dementia to deliver an intervention that was best suited to their needs using an interaction-focussed life story approach.

My main finding was that life story work provided enjoyable and positive experiences for the person with semantic dementia and their family, but that the *format* and *delivery* of the approach *needed to be adapted to the person's specific needs at that point in time*. For example, I worked alongside Sarah and her family to develop a biographically grounded and meaningful life story music DVD that enabled Sarah to 'sing along' and become centre stage within the family interaction. Words sung from the songs, such as 'cheek to cheek' and 'love' were not only understood, but they were performed by Sarah as acts of affection and togetherness with her family. In another example, Ruby and Brian made life story books together. Whilst Ruby could not always remember the places in the photographs she loved to talk about the different clothes she wore, appearance being a key aspect to her identity.

Whilst as researchers we tend to focus on outcomes such as behaviour or aspects of communication displayed, families valued opportunities to connect with the person with semantic dementia and simply 'have fun' together. Some aspects of adapting the interaction-focussed life story approach related to particular cognitive issues in semantic dementia e.g. difficulty recognising people and places in photographs or difficulty remembering certain events from long term memory. Other challenges related to issues of personality change and where to place new found interests and behaviours within the life story work. I found that whilst life story books were useful for some individuals or at certain stages, alternative formats were also needed and music was often central to this. Interaction-focussed life story work needs to take account of the person *as they are now* and their current interests and not to rely solely on the past, as is common in using this approach in Alzheimer's disease, for example. Interaction-focussed life story work also provided a vehicle to help others understand the person and their identity, such as helping care workers to understand the needs and behaviours of an individual and how this could be used to facilitate person centred care and interaction.

I intend to do more research examining this approach and would be interested in hearing from any carers, people with dementia and/or professionals who have any experience of using life story work in the rarer dementias to help further inform my work. Please email: jaqueline.kindell@manchester.ac.uk.

Please see below for details of forthcoming meetings:

FTD London Carers Support Group Meeting - 9th January 2017

Date: Monday 9th January 2017, **Time:** The meeting will run from 11am - 2pm, with coffee available from 10.30am and lunch provided, **Location:** The Wellcome Collection, 183 Euston Rd, London. NW1 2BE.

Directions: <https://wellcomecollection.org/visit-us/getting-here>

Agenda will include an introduction to the “Created Out of Mind” project and introduction to the resident artists – from Professor Seb Crutch, Clinical and Research Neuropsychologist and Emilie Brotherhood, Created Out of Mind Project Manager. After lunch, Lucy Russell, a Research Assistant at the UCL Dementia Research Centre will talk about the LIFTD project she is currently involved in as well as her PhD research project which is looking at eye-tracking to assess social cognition in FTD. There will also be ample opportunity to work directly with the artists or engage in small group discussions with other people who live with or know someone with FTD.

FTD ANNUAL SEMINAR - 2nd MARCH 2017

Date: Thursday 2nd March 2017, **Time:** 9.30am - 4pm, **Location:** The Basement Lecture Theatre: 33 Queen Square, London. WC1N 3BG.

Provisional agenda to include:

An overview of FTD - Dr Matthew Jones, Consultant Neurologist, Salford Royal NHS Foundation Trust.

Sexuality and Intimacy: The impact of a dementia diagnosis - Speaker TBC.

The use of lumbar punctures for the diagnosis of, and research into, dementia and FTD - Dr Ione Woollacott, Neurology registrar, Dementia Research Centre, UCL.

Understanding FTD through blood and spinal fluid measures - Dr Jon Rohrer, Consultant Neurologist, Dementia Research Centre, UCL.

‘What’s On Your Mind..?’ a question and answer session - Prof. Nick Fox, Director, Dementia Research Centre, UCL.

Interaction-focussed Life Story Work in Semantic Dementia - Dr Jackie Kindell Speech and Language Therapist, The University of Manchester.

Frontotemporal Dementia: A personal perspective - Shaheen Larrieux.

To register your interest please email Janette Junghaus (j.junghaus@wellcome.ac.uk) or telephone 07341 776 317.

Cost: £75 for professionals, £10 family members (discretionary rates apply)

Dates for your 2017 diary...

Joint Carer’s Support Group Meeting - 6th February 2017
Bereaved Carer’s Support Group Meeting - 29th March 2017
London PPA Support Group Meeting - 27th April 2017
London FTD Carer’s Support Group Meeting - 12th June 2017

To register interest at any of the above meetings, please email Janette Junghaus (j.junghaus@wellcome.ac.uk) or telephone 07341 776 317.

Regional Facilitators Contact Details

FTDSG Volunteer Regional Facilitators

For carers, there is often a sense of isolation when faced with the distress and burden that frontotemporal dementias cause. In some areas support group meetings are arranged by volunteer regional coordinators. Please contact regional coordinators directly:

Scotland: Anne Miller - 01877382654 milleranne89@googlemail.com .

Yorkshire: Rev. Ronald Carter - 01904 610 237 and Anne Squires - 0113 2947139.

Manchester/ Stockport: Helen Griffiths - 0161 716 4505 or helen.griffiths@nhs.net.

Mersey and North West: Mrs Mary Dawber - 01625 879 104 or mary1246@hotmail.co.uk.

West Midlands: Sister Ann Johnson - 01743 210097.

Birmingham: Pauline Ross - 07815285876 or polly.ross@btopenworld.com and Kirsty O'Dwyer - 07887800947 or kross38@hotmail.com. Kirsty is happy to take calls from anyone whose parent is affected by FTD .

London: Rob Perry - robertkperry@live.co.uk or 07812 393968.

Central: Emeline Keown [Young Dementia UK] - 07909 060430 or emeline-keown@youngdementiauk.org.

Northamptonshire: Hilda Hayo - 07920 819523 or hhayo@talk21.com .

Camb: Val Freestone - 01223 768005 or valerie.freestone@addenbrookes.nhs.uk.

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

Kent/Sussex: Jane Smissen Bell - 01323 504156 or 6bells.jane@gmail.com.

West Sussex: Jill Butcher - 01444 451 837 or jillbutcher@onetel.com.

South West: Miss Penelope Roques - 01297 445 488 or frontotemp@aol.com.

Cornwall: Mrs Cindy Reeve - 01726 71562

Lynne Ramsay acts as a volunteer adviser on funding and services: 0208 467 1462 or mobile 07760224396 or email lynneramsay1@gmail.com.

Rare Dementia Support runs specialist support group services for individuals living with, or affected by, one of five rare dementia diagnoses: frontotemporal dementia (FTD), posterior cortical atrophy (PCA), primary progressive aphasia (PPA), familial Alzheimer's disease (FAD) & familial frontotemporal dementia (fFTD).

Our vision is for all individuals with or at risk of one of these rarer forms of dementia to have access to specialist information, support and contact with others affected by similar conditions.

Rare Dementia Support is a Fund held by the National Brain Appeal (registered charity number: 290173)

Rare Dementia Support activities are charitably funded—for information on how to make a donation please go to bit.ly/RDSfund.



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