



## FTD Support Group newsletter - May 2019

### Next meeting – July 4<sup>th</sup>

Welcome to the May 2019 edition of the FTD Support Group newsletter. You will find the latest updates on all of the activities, events and opportunities across the FTD community, as well as useful resources.

#### Our Next Meeting

## *Save the date!*

The next meeting will be held on **4<sup>th</sup> July 2019**.

Dr Liz Sampson, a clinical reader in old age psychiatry at UCL will talk about pain assessment and management in FTD and motor neuron disease . Afterwards, one of our members will give a short talk on her experience with RDS.

After lunch we will break into discussion groups. These will include a discussions about activities for those with FTD and FTD research at the Dementia Research Centre.

The agenda is subject to change, but we hope this gives you an idea of what you might expect on the day.

Your experiences are important in driving these discussions and we would really appreciate your opinions and advice.

At our last meeting we held a pre-meeting for new members which many found useful so we will be running another one at the support group on 4<sup>th</sup> July. This will take place at 10:00am.

Details of the event are as follows:

#### **Date and Time:**

Thursday 4<sup>th</sup> July 2019, 11:00 – 14:00  
(10:00am for pre-meeting)

#### **Location:**

6<sup>th</sup> Floor, Wellcome Trust, Gibbs Building, 215 Euston Road, London, NW1 2BE

An invitation will be sent out to all members with instruction on how to RSVP in due course. For any enquires, please contact Hannah Carr by email at [Hannah.carr@ucl.ac.uk](mailto:Hannah.carr@ucl.ac.uk).

#### **Travel Costs**

We are aware that some people travel long distances to attend our meetings, and may require financial support. The National Brain Appeal's Rare Dementia Support Fund helps to fund some of these travel costs for those who need it.

If you need some help with travel expenses to attend meetings, please let Hannah Carr know by emailing [Hannah.carr@ucl.ac.uk](mailto:Hannah.carr@ucl.ac.uk).

## FTD Annual Seminar

Thank you to everyone who came along to the FTD Annual Seminar on 22<sup>nd</sup> March. There was a great turn out and we hope that you found it useful.

If you were unable to attend, recordings of the talks are available on our website under the "Recordings" tab on the FTD homepage. They can also be accessed on the RDS YouTube Channel:

<https://www.youtube.com/watch?v=pgtJKz-a7G0>



The seminar included talks from a range of speakers including researchers, a speech therapist and one of our members. At the end of the seminar Professor Nick Fox ran a Q&A Session. Prof. Fox also provided an update of plans for the new Rare Dementia Support Centre, which is still in early stages. This can all be viewed at the end of the FTD Annual Seminar recording.

We would like to hear your feedback on the FTD Annual Seminar. The day is designed for you so it is very important for us to collect your feedback, to ensure you get the most out of the day as possible.

If you would like to share your feedback with us, please contact Hannah at [Hannah.carr@ucl.ac.uk](mailto:Hannah.carr@ucl.ac.uk)

## Locking cooker valve

At the FTD Annual Seminar we were made aware of SGN. SGN is offering a **free** safety device to help vulnerable people keep gas safe in their own homes. The locking cooker valve prevents someone from unintentionally turning on or leaving on a gas cooker. This allows someone with dementia to retain their independence whilst remaining safe at home. For more information visit their website at <https://www.sgn.co.uk/LCV/>.



## Alzheimer's Research UK

Would you like to help increase understanding and raise the profile of FTD?

We are working with Alzheimer's Research UK – the UK's leading dementia research charity – to raise awareness and understanding of the challenges and demands of this disease. They would love to talk to people like you about your experiences of living with FTD, to help them raise awareness in the media. This not only ensures that more of the general public are aware of FTD – vital in challenging stigma - but also helps to highlight the importance of research and make breakthroughs possible.

If you would like to help, and you would feel comfortable chatting to one of their friendly communications officers, then you can either drop an email to [stories@alzheimersresearchuk.org](mailto:stories@alzheimersresearchuk.org) or email Hannah Carr at [Hannah.carr@ucl.ac.uk](mailto:Hannah.carr@ucl.ac.uk), who will be happy to talk things through with you.

## ESRC-NIHR Dementia Initiative 2018:



We are delighted to announce that Prof. Seb Crutch has been awarded funding as part of a £15 million ESRC-NIHR initiative on research into improving the lives of people living with dementia. This was awarded alongside a team of both national and international colleagues at Bangor University, Canterbury University and Nipissing University.

The proposed project will focus on understanding and developing support group services for those living with a rare dementia. Specifically, it will focus on developing an online support group that can be accessed from anywhere. The project will therefore build on the face-to-face support group meetings that run across the country.

Prof. Crutch has commented on the project saying **“We’re thrilled that the ESRC-NIHR have agreed to fund this work looking at the value of support groups by, with and for people with young onset and rare dementias. The support groups grew initially out of our local London clinic, but we have a vision that everyone living with, or at risk of living with, a rare form of dementia has access to specialist information, support and contact with others affected by similar conditions.”**

For more information and to read the press release, please follow this link: <https://esrc.ukri.org/news-events-and-publications/news/news-items/new-research-to-provide-virtual-support-for-people-with-rare-dementias/>

## RDS Website

We are currently planning some exciting new developments to improve the Rare Dementia Support (RDS) service. As part of this, we are exploring ways in which we can improve the RDS website (<http://www.raredementiasupport.org/>) so people living with rare dementias, their loved ones, carers and those that work with them can more easily access the information and support they need.

We want to better understand what information you need, how you currently use the website and what changes we could make to better support you. If you could please take a couple of minutes to answer 4 questions, it would be greatly appreciated. Please submit your answers at this link:

<https://opinio.ucl.ac.uk/s?s=60319>.

- **What are the first question(s) you have once you/a family member/partner/ friend is diagnosed with a dementia?**
- **What kind of information are you looking for when you search the internet about rare dementias?**
- **Are there any obstacles to accessing or using the RDS website?**
- **What changes can we make to the RDS website to better support you?**

We are continuously making changes to improve the RDS service. There will be a



## Saying Hello

Many of you would have met Nikki Zimmermann at the FTD Annual Seminar. Nikki joined the team in the new year as the RDS Groups Advisor. She has a background in public health and has worked for the Alzheimer's Society for seven years. We are excited to have Nikki join the team, bringing the breadth of experience she has with her!

We would also like to welcome Siobhan Culley and Claire Waddington. Siobhan and Claire will be working on the new RDS Impact Study and you will likely see them both at the next FTD Support Group.

### **Other upcoming meetings**

Below is a list of the upcoming Rare Dementia Support meetings in 2019:

**Bereaved Carers Support Group Meeting** – Wednesday 19<sup>th</sup> June 2019 - Boardroom at National Hospital for Neurology and Neurosurgery, Queens Square, London WC1N 3BG

**PCA Support Group Meeting** – Friday 5<sup>th</sup> July 2019 - 6<sup>th</sup> Floor Conference Suite, Wellcome Trust

**PPA Support Group Meeting** – Tuesday 23<sup>rd</sup> July 2019 - 6<sup>th</sup> Floor Conference Suite, Wellcome Trust

For more information on these events you can also email the team at:

[contact@raredementiasupport.org.uk](mailto:contact@raredementiasupport.org.uk)

For information on other regional support groups taking place please visit our website:

<http://www.raredementiasupport.org/meetings/>

Finally, we wanted to remind you that you are always welcome to contact the Rare Dementia Support Team for advice and support on your journey with FTD, at [contact@raredementiasupport.org](mailto:contact@raredementiasupport.org)

Thanks you as always for you support, stories and feedback.

Yours,

**The FTD Support Group Team**

### **DISCLAIMER**

*Please note that you assume full responsibility and risk in the use of information contained on our website, in our newsletters, at support group meetings and in subsequent correspondence. Our support group-based correspondence is generic in nature and we are limited in our ability to offer specific advice via this means. 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.*

*Our regional group facilitators are volunteers. They may refer to regional facilitator guidelines from RDS but are not governed by RDS. They operate independently and with best intention and you assume full responsibility for your contact and engagement with them and in the regional groups they facilitate. Please see the clinician responsible for your care, a social services representative, or your GP if you have specific needs which require attention. Any medical decisions should be taken in discussion with an appropriate health care professional.*