



Cognitive Neurology Support Services
nikki@cog-neuro-support.com

ST GEORGE'S YOUNG ONSET SUPPORT GROUP

This is the July Newsletter for St George's Young Onset Support Group and an enormous thank you to all the wonderful people who have contributed to make this group so fantastic so far this year. What a very difficult year this has been! The Coronavirus hit the world like a ton of bricks and on March 23rd England was put into lockdown. This meant a halt on Support Group meetings, but not a halt on support. We have adapted to ensure we are always here to support you. We are currently providing 'virtual' support.

History of St George's Young Onset Support Group

The Cognitive Neurology Service at St George's Hospital was established in 2010 to provide a specialist service for people with cognitive neurological problems including dementia. It now sees approximately 300 new patients each year. Many of these cases are people with young onset dementia. The Support Group was set up to provide a space for people in similar situations to meet each other, gain information and advice and feel supported and not so isolated. The Support Group format has changed over the years with different providers and different needs from the group members. In January 2019, Cognitive Neurology Support Services officially became the facilitators of the group with the aim to have all support group members fully proactive in the group.

Staff – who are we??

Nikki Zimmermann - 10 years' experience with Young Onset Dementia and working in the clinics at St George's alongside the Neurology Consultants. Direct Support Lead at Rare Dementia Support, UCL.

Elaine Eager – St George's YOD Dementia Support Worker and Carer Mentor with heaps of experience

Darren Annon – Local Health and Fitness Coach and Advisor on wellbeing and exercise.

Due to the changes, we have been without our lovely volunteers Alexis and Matt for a while, but we do keep in regular contact and they very kindly keep us updated with news on Home Care Support with the impact of Coronavirus and extra services they have put on.

Alexis Cibrano – Qualified Social Worker and Dementia Service Manager, Sweet Tree Home Care

Matt Mills – General Home Care and Dementia Services Director, Sweet Tree Home Care

They have been incredibly busy with courses and events and here is the latest

info: <https://www.sweettree.co.uk/webinar-session-in-partnership-with-the-alzheimers-show/>

THE BENEFITS OF SPECIALISED LIVE-IN CARE FOR DEMENTIA AND PRACTICAL TIPS AND TRICKS FOR FAMILY CARERS



Tuesday 28th July 11:00 – 12:00

Alexis Cibrano, Dementia Service Manager & Clinical Specialist, SweetTree Home Care Services

Specialised live-in care for Dementia and practical tips and tricks for family carers.

Can anyone become a 'Expert' Dementia Carer? The SweetTree Care Academy arms our carers with the tools to enable those with Dementia to find value in their world, we look to share some of our teachings and experiences that will hopefully result in tangible benefits for you and your loved ones. As well as insight - we uncover the invaluable role that specialist live-in care has to play in managing dementia in the future. 40 minute presentation and 20 minute Q&A.

Elaine's Role

We are so lucky to have Elaine involved in the Young Onset Support Group. Elaine has been involved with the support group for many years as a carer to her lovely husband Paul who has LPA. Elaine is now a Carer Mentor at the group, which is a vital part of the support group and one truly valued by the members. Elaine started a new role at St George's in 2019 as Young Onset Dementia Support Worker. This role provides peri and post diagnostic support for people under the age of 65. Elaine has been present at many appointments when the diagnosis is given and can provide valuable immediate post diagnostic support and comfort. She is there to provide an empathetic listening ear, source information and be available for ongoing support for as long as the person living with dementia and family needs it.

Contact: Elaine.Eager@stgeorges.nhs.uk



Changes in Hospital Appointments

As many of you will be aware that outpatient's appointments were changed to telephone and videocall appointments during lockdown. This was in line with most working people (where they could) working from home. We have all discovered new ways of working and how we can actually be more productive WHILST keeping people safe. Going forward we will be seeing adaptations to appointments. There will be face to face appointments when needed but many appointments will be conducted via videocall unless there is a need for physical

examinations. This will reduce the stress of travelling to appointments and parking fees. Contact with the Consultants and Nurses have not stopped and contact can always be made to the Cognitive Neurology Team via Elaine.

Nursing Team Update

CNS Jen Tulloch who most of you know very well, has returned to clinic after spending the last few months on the COVID19 frontline bravely working in the Intensive Care Unit.

Sadly, Diana Mukonoweshuro has left St George's to work as a Parkinson's Nurse at Kingston Hospital. Moira Rowan will now be sharing the Nursing Clinics with Jen. Again, Elaine can liaise with the Nursing Team. Both Diana and Moira have worked intensively with the Cognitive Neurology Team as Dementia and Delirium Nurses.

St George's Young Onset Support Group Calendar of Events 2020

January	Christmas stories and shared coping strategies	Peer Support Groups
February	Music for Life Session	Wigmore Hall
March	Lockdown – Coronavirus impact	Weekly Newsletters Resources and Coping Tips
April	Lockdown – Coronavirus impact	connect2culture Webinar Mini series Interactive quizzes
May	Zoom Support Groups started fortnightly	Contented Dementia Vs Validation Theory
June	Zoom Support Groups	Quiz/Peer Support

July	Zoom Support Groups	Support Group planning/YPLWD Reminiscence
August	My Life Films presentation via Zoom	Charlotte George
September	tba	
October	tba	
November	tba	
December	tba	

To Zoom or not to Zoom?

When the lockdown was introduced in March, we really didn't know what the impact would be on services and how long it would last. We have stayed connected with members by email and telephone and liaised with hospital staff with any issues. Initially we corresponded through weekly emails providing essential COVID19 related information and sourcing online resources to keep people stimulated and informed. We know this was not a perfect substitute but felt it helped towards some daily routines albeit living our lives on a virtual platform. We are also aware of the limitations for those with a cognitive impairment. In May, we expanded by joining the technical world and started our Support Group Meetings via Zoom. Again, we realised these are not accessible for everyone and they can be quite difficult especially when there are lots of people in the 'Zoom Room'. For this reason, we have increased this to fortnightly rather than monthly meetings and mixed them up so some are carer based, some for people with a diagnosis so they have chance to discuss issues or share stories and some for both with a quiz or a presentation from an external organization. By separating these out we have less people per session but this is more manageable using this format, and hopefully this provides something for everyone.

Impact of Covid 19

Thank you to all the members who sent through their experiences of the impact has had on them and their loved ones. From disruption to routines and missing activities, missing going out for lunch or coffee and cake to decline in functioning and physical ability to not being able to visit loved ones in care homes, the impact has been devastating and isolating for all. We will be putting together some documents on these shared experiences soon and the concerns about the new 'normal'. Please send any experiences you wish to share with me and they will be used anonymously. nikki@cog-neuro-support.com

Feedback

Here are some lovely words from our members.....

The meetings at St George's were emotionally supportive (and we were able to have a laugh) we were all bound together because we understood what we were all going through and the bleak future we faced. I have spoken to both Nikki and Elaine on many occasions about my husband they are both empathetic and knowledgeable, not least very kind.

It was comforting to know that we were not alone after we had had a diagnosis that had left us devastated, to know that there were others who were experiencing similar to us and would be there to guide us. The humour of the group and the sense of just carrying was a good antidote to the sense of catastrophe that the diagnosis brought (that sense of 'that's it, it's all over, what do we do now?') Since the weekly Zoom meeting was set up it has become more important still as a lifeline to the outside world after the claustrophobia of the lockdown with the added sense of isolation. It has been great to be able to get together again.

The group has been a focus for us to learn more about the disease and the services that are available to us. We have both found it valuable, mainly to understand more about dementia and the latest thinking and research on how best to treat it. The group is also a forum where, as a carer, I can share experience with other carers and learn more about what is available to support us.

Fundraising Activity

Claire and Sophie Hack are very kindly taking part in a Fundraiser Bike Ride for the Young Onset Dementia Support Group on Sunday 16th August. They will be cycling 65 miles from their home in Farnham weaving through London and finishing at Tooting Bec Common. Barney the dog will be keeping them company in a bike basket. Claire and Sophie support Claire's Mum Linda who lives with a diagnosis of PCA and they have been coming to the support group meetings for the last couple of years. Claire describes the group as *'One big happy family'*

Please encourage friends and family to sponsor Claire and Sophie on the link below as this is such a generous gesture.

<https://www.justgiving.com/campaign/YODsupportgroup>



Young Onset Support Group Zoom Dates 2020

Wednesday 29th July - Quiz

Wednesday 12th August – My Life Films

Wednesday 26th August – Carers Group

Wednesday 9th September – YOD Group

Wednesday 23rd September – joint tba

*Zoom meetings take place every fortnight on a Wednesday at 7pm. Please contact nikki@cog-neuro-support.com for details and joining instructions

Do you have a Rare Type of Dementia?

- (FTD) Frontotemporal Dementia
- (PPA) Primary Progressive Aphasia, Semantic dementia. Progressive non-Fluent Aphasia, Logopenic Aphasia
- (PCA) Posterior Cortical Atrophy
- (DLB) Dementia with Lewy's Bodies
- (fAD) Familial Alzheimer's Disease

If you do please visit the www.raredementiasupport.org and find specific information, receive newsletters and invitations to the National Support Groups which are currently taking place using a Webinar format. There are also Small Group Discussion, where you can 'virtually' meet others in similar circumstance. These are topic focused groups such as: Empowering your Identity, Independence and Identity, Advanced Care Planning and Pre – Bereavement Grief.

SUPPORT RESOURCES

Social Services – Needs Assessments and Carers Assessments

PLEASE NOTE THESE ARE STILL CONTINUING BUT THROUGH TELEPHONE CONSULTATION. LOCAL AUTHORITIES HAVE ALSO BEEN GIVEN EXTRA FUNDS TO ENSURE THERE IS NOT A DELAY IN THESE

A care needs assessment - or social care assessment – available from your local council, can be the first step towards getting the help and support you need with your everyday life. The aim of a care needs assessment is to work out how much help you need - to enable you to live as independently as possible! This is recommended as soon as any support is required, as it gives a good benchmark for any continuing needs. There's no charge for a care assessment and you're entitled to one regardless of your income and savings, and regardless of what your needs are.

*Wherever you live we recommend you are in touch with your local Alzheimer's Society, Carers Centre, Age UK, Citizens Advice Bureau

.Alzheimer's Society Offices

Merton 020 86870922 merton@alzheimers.org.uk

Wandsworth 020 86780922 wandsworth@alzheimers.org.uk

Richmond 020 8036 9570 richmond@alzheimers.org.uk

Kingston 020 35135147 kingston@alzheimers.org.uk

Sutton 020 87701875 sutton@alzheimers.org.uk

Croydon 020 86532818 croydon@alzheimers.org.uk

Surrey 01932 855582 surrey@alzheimers.org.uk

IAPT contacts

IAPT is primarily for people who have mild to moderate mental health difficulties, such as depression, anxiety, phobias and post-traumatic stress disorder. These conditions are treated using a variety of therapeutic techniques, including cognitive behavioural therapy (CBT), interpersonal therapy (IPT) and couples therapy. IAPT (Improving Access to Psychological Therapies) is a national programme established in 2005 after it was recognised a large percentage of the population suffer with problems like depression and anxiety

Talk Wandsworth 020 3513626 <https://www.talkwandsworth.nhs.uk/>

Merton IAPT 020 38239063 <https://www.mertonuplift.nhs.uk/iapt>

Richmond Wellbeing Service 020 85485550 <https://www.richmondwellbeing.nhs.uk/>

Kingston ICope 020 33177850 <https://www.icope.nhs.uk/kingston/>

Sutton Uplift 020 3 5134044 <https://www.suttonuplift.co.uk/>

Croydon IAPT 020 32284040 <https://slam-iapt.nhs.uk/croydon/welcome-to-croydon-iapt/>

Our Mind Matters Surrey 020 71834201 <https://www.healthysurrey.org.uk/covid/psychological-support>

Dementia UK

Admiral Nurses provide the specialist dementia support that families need. When things get challenging or difficult, our nurses work alongside the entire family, giving them one-to-one support, expert guidance and practical solution

Dementia Helpline 0800 888 6678 or helpline@dementiauk.org

Many thanks for all your help and support for making this a unique and wonderful support group. Please share this fundraising link with family and friends to enable us to continue with the Young Onset Support Group

<https://www.justgiving.com/fundraising/youngonsetdementiasupportgroup>