



Cognitive Neurology Support Services  
[nikki@cog-neuro-support.com](mailto:nikki@cog-neuro-support.com)

# ST GEORGE'S YOUNG ONSET SUPPORT GROUP

This is the Autumn Newsletter for St George's Young Onset Support Group; I can't quite believe we are at the end of October already! Thank you to all the wonderful people who have contributed to make this group so fantastic so far this year. It has been a very difficult year and we are heading to a very uncertain time ahead. Unfortunately no physical meet ups however, this will mean the Support Group meetings will be continuing with the fortnightly Zoom meetings for the next six months. Please remember this is not a halt on support and we are aware this is not a suitable format for everyone, so please make contact by email if you need to discuss issues at any time and we ensure we are always here to support you.

## 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.

Contact: [nikki@cog-neuro-support.com](mailto:nikki@cog-neuro-support.com)



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

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 is available 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](mailto:Elaine.Eager@stgeorges.nhs.uk)



## News from Alexis

Many of you will remember Alexis who has been volunteering with the group for the last few years. Alexis was instrumental in providing up to date information from the social care background and full of advice for those looking for support at home. I am delighted to bring wonderful news – the safe arrival of Mila Rose.

Here is the special message from Alexis:

*“Mila Rose was born 7<sup>th</sup> Septembers at a whole 2.52kg and 19inches (48.5cm). She was quite the string bean! Long and skinny with long legs, lucky her. She is her dad’s twin and is feisty as anything. We are just through the first month - chaotic overwhelming exhausting joy and elation is how I would explain it. My gosh, infants are miniature adorable tyrants. More so because I am exclusively breastfeeding so she has mom on demand round the clock.*

*Everyone said they change so fast but I didn’t quite comprehend it! She’s put on 2+lbs since birth and she’s looking pretty different which is amazing.*

*A big hello to everyone at the St George’s Young Onset Group, I’d love to join a zoom soon. I’m getting the hang of being showered and dressed before 5pm now”... Much love Alexis*



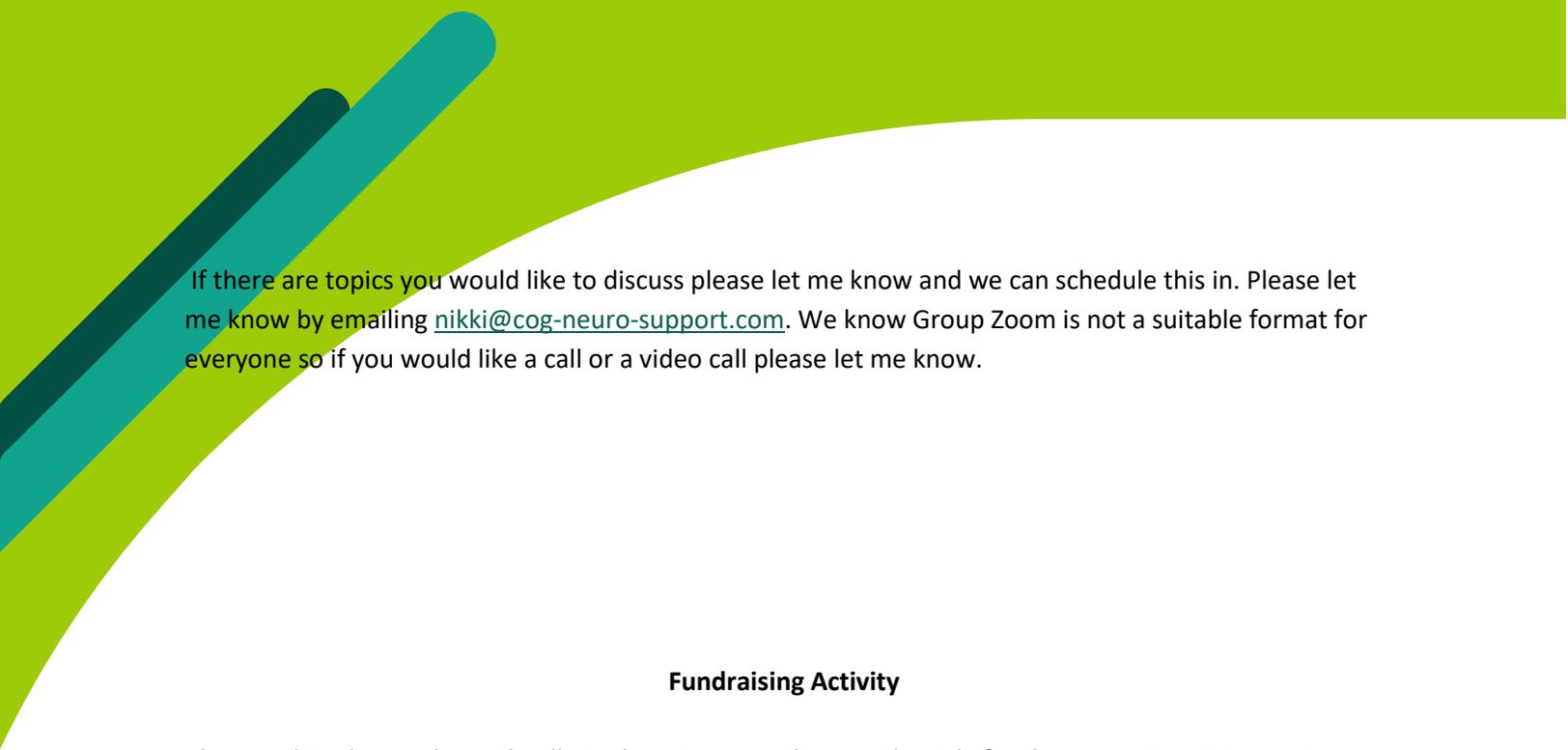
## **Changes in Hospital Appointments**

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.

## **We are not Boomers, we are Zoomers!**

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 this has provided something for everyone.

Recently we have had a presentation from My Life Films, had a quiz, did some reminiscing about University, first work places and even first dates!!! We have talked about emergency planning and unexpected hospital admissions and also about staying active and motivated.



If there are topics you would like to discuss please let me know and we can schedule this in. Please let me know by emailing [nikki@cog-neuro-support.com](mailto:nikki@cog-neuro-support.com). We know Group Zoom is not a suitable format for everyone so if you would like a call or a video call please let me know.

### **Fundraising Activity**

Claire and Sophie Hack very kindly took part in a Fundraiser Bike Ride for the Young Onset Dementia Support Group on Sunday 16<sup>th</sup> August. They successfully cycled 65 miles from their home in Farnham weaving through London and finishing at Tooting Bec Common with Barney their dog in a bike basket. Claire's very proud Mum Linda, who lives with a diagnosis of PCA and has been attending the support group meetings with her devoted family for the last couple of years. Claire describes the group as *'One big happy family'*

Claire and Sophie smashed the target of £2,000 which we are all so utterly grateful for – so thank you to everyone who generously donated and a huge thank you to Claire and Sophie for doing this for us all.

If you didn't manage to donate and want to you still can via this link  
<https://www.justgiving.com/campaign/YODsupportgroup>

**A huge Thank You Claire and Sophie!**





### **Fundraising News from St George's Charity**

Please see enclosed details from the St George's Charity Fundraising Team with a list of exciting challenges

## 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](http://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.



## Being Prepared

We discussed at our recent Zoom meetings about being prepared for all eventualities and making sure you had all paperwork in place and plans in case there was an emergency.

- Make sure you have a 'This is Me' completed in case of hospital admissions unexpectedly

[https://www.alzheimers.org.uk/sites/default/files/2020-03/this\\_is\\_me\\_1553.pdf](https://www.alzheimers.org.uk/sites/default/files/2020-03/this_is_me_1553.pdf)

- Make sure you are registered with the Carers Centre in your area (this is the Wandsworth one)

<https://www.wandsworth.gov.uk/health-and-social-care/adult-social-care/adult-social-care-information-and-advice/looking-after-someone/getting-help-in-a-emergency/>

- Lasting Power of Attorney – make sure you have both Health and Welfare along with Legal and Financial

<https://www.gov.uk/power-of-attorney>

## 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](mailto:merton@alzheimers.org.uk)

Wandsworth 020 86780922 [wandsworth@alzheimers.org.uk](mailto:wandsworth@alzheimers.org.uk)

Richmond 020 8036 9570 [richmond@alzheimers.org.uk](mailto:richmond@alzheimers.org.uk)

Kingston 020 35135147 [kingston@alzheimers.org.uk](mailto:kingston@alzheimers.org.uk)

Sutton 020 87701875 [sutton@alzheimers.org.uk](mailto:sutton@alzheimers.org.uk)

Croydon 020 86532818 [croydon@alzheimers.org.uk](mailto:croydon@alzheimers.org.uk)

Surrey 01932 855582 [surrey@alzheimers.org.uk](mailto: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.richmondwellbeingservice.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](mailto:helpline@dementiauk.org)

### **Young Dementia Network**

We believe that everyone affected should be well informed, feel connected to others and enabled to live life to the full. Young Dementia UK have created 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.

<https://www.youngdementiauk.org/young-dementia-network>

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>

**Young Onset Support Group Zoom Dates 2020**

Wednesday 21<sup>st</sup> October - Carers

Wednesday 4<sup>th</sup> November – Joint

Wednesday 18<sup>th</sup> November – YOD group

Wednesday 2<sup>nd</sup> December – Carers Group

Wednesday 16<sup>th</sup> December – joint Christmas

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

