



Cognitive Neurology Support Services  
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**ST GEORGE'S YOUNG ONSET SUPPORT GROUP**  
**DECEMBER 2020 Newsletter**

Welcome to the end of year newsletter for St George's Young Onset Support Group, and what a difficult year it has been. Thank you to all the wonderful people who helped to keep us connected this year. Lockdown brought fear and panic to all households, but more so to those more vulnerable. It took away activities and routines, resulting in the lack of stimulation and socialising which had a detrimental impact on many people. We have seen such a change in our lives over the last nine months, with only having a slight reprieve in the summer. We are now almost back where it started.

The new strain of the virus has made it more important than ever to keep safe and in Tier 4 restrictions are in place to try and protect us all. We have all experienced the quietest Christmas festivities ever and missed family and friends we would have like to have seen. We hope we will be able to be reunited once times are safer. Due to keeping everyone safe we will continue this year to use Zoom for our Support Group Meetings. I am aware this is not a suitable format for all and I do apologise, however this is all we can offer at present to keep safe. The Zoom meetings are twice a month and we try to cater for all needs as much as possible. If you haven't yet tried it please come along and give it a go



### **The History of St George's YOD 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. Cognitive Neurology Support Services has been facilitating the group for the past couple of years and we have tried to keep you all connected throughout the pandemic. Over the past nine months we have converted our sessions to an online platform allowing us to meet in the safety and comfort in our own homes by Zoom. We have experimented with varying the sessions and most recently increased the sessions to twice a month and separated sessions for those with a diagnosis and those caring for someone. This has been most helpful at meeting the variation of needs. We also have occasional joint sessions.



**Staff – who are we ??**

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

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

**Darren Annon** – Local Health and Fitness Coach available to advise on wellbeing and exercise

**Alexis Cibrano** - Qualified Social Worker and Dementia Service Manager, Sweet Tree Home Care. During lockdown Alexis continued to be a great source of support providing the vital updates from the Home Care industry throughout. She then went on maternity leave and here is what arrived - Mila Rose!



So, let's look at what happened this year.....

We have **81** Members on the database

We only had two physical meetings this year and **40** people attended the meetings

We sent weekly newsletters to all members from the end of March to May these included the latest updates, how to keep safe, what services were available, coping strategies, online activities and resources and a weekly Exercise Class from Darren the PT Coach.

In May, we all got very brave and converted to Zoom where we have been continuing to meet fortnightly.

During the summer months when we were allowed a small group safely met for a socially distanced walk at Nonsuch Park. We also gathered at Tooting Common to celebrate Claire and Sophie Hack arriving at the final of their Cycle ride Fundraiser for St George's Young Onset Service

<b>January</b>	<b>Christmas Stories and Coping Strategies</b>	<b>21</b>
<b>February</b>	<b>Music for Life</b>	<b>Wigmore Hall Musicians 29</b>
<b>March</b>	<b>Lockdown</b>	<b>Weekly Newsletters began</b>
<b>April</b>	<b>Lockdown</b>	<b>Connect2culture Webinar Mini series Interactive quizzes</b>
<b>May</b>	<b>Zoom Support Groups started fortnightly</b>	<b>Contented Dementia Vs Validation Theory</b>
<b>June</b>	<b>Zoom</b>	<b>Quiz/Peer Support</b>
<b>July</b>	<b>Zoom</b>	<b>Support Group planning/YPLWD Reminiscence</b>
<b>August</b>	<b>Zoom</b> <b>St George's Charity Bike Ride</b>	<b>My Life Films presentation with Charlotte George</b>
<b>September</b>	<b>Zoom changed to alternating Carers/YPLWD/Joint</b>	<b>Summer Holidays Memories Quiz</b>

<b>October</b>	<b>Zoom</b>	
<b>November</b>	<b>Zoom moved to two separate sessions each fortnight due to Carer Stress</b>	
<b>December</b>	<b>Art Project Discussion</b> <b>Music for Life Christmas Music Session</b>	<b>Tash Clarke and Lisa Temple Cox</b> <b>Wigmore Hall Musicians</b>

We were delighted to provide an extra session at Christmas time for the group members, this was beautifully facilitated by Caroline, Lydia and Sylvia from Music for Life. Please see the attached flyers from the Wigmore Hall Team about the Monday sessions of Music for Life which you are welcome to join and you can contact Sylvia directly

We will also be introducing some monthly Art sessions in our groups; these will be incorporated into the 4<sup>th</sup> week session each month in the 7-8pm slot but there will still be time to chat and socialise.

Here are some of the outcomes we achieved...

Long lists of online activities	Resources for Hospital Admissions and guidance throughout	Fitness and exercise videos	Developing online Art Therapy Programme
List of Coping Strategies Cognitive Stimulation	Shared stories and life experience s	Opportunities to have life films made by My Life Films	Lots of fun and social interaction
Resources and where to go for help during the pandemic	The joy of participating in music sessions online	Sharing carers experiences and tips	Emergency contact sheets and processes

In a troubled year we hope we have provided benefits for all affected by young onset dementia, living with or caring for.

**Members told us how they feel:**

- Less isolated
- Local support structure via zoom
- Increased confidence in Zoom participation
- Meeting others with similar issues and sharing stories on Zoom
- Zoom Buddies
- Opportunity to ask questions and gain information

**We have been told of the benefits for Carers**

- Experiences and advice from others
- Information for caring role
- Mutual Support in a difficult time
- Coping Strategies
- Internal Carer WhatsApp Group

**Certain things we have helped with:**

**Hospital admissions** – Having links with the staff at St George’s and especially having Elaine integrated as part of the team has been most helpful for those unfortunate times when unexpected hospital admissions have occurred. It has helped with communication and ensured safely discharged patients back to their homes. This has not always been easy but hopefully eased the pathway.

**Carers Assessments** – These were still ongoing during the pandemics and as situations at home changed it was important these were carried out and updated. Registering as a Carer was more important now than ever.

**Clinic appointments** – ensuring members continued to have their clinic appointments was vital through lockdown. This often meant a telephone or video call due to safety but the services adapted and we made sure people were getting access

**Calling the GP** – there have been a few times this year when worried members have had concerns with sudden changes. We have made sure we give the correct advice and request interventions from the GP asap when required.

**And we had some lovely quotes in the feedback.....**

We have been attending the support group of YOD at SGH since my husband's diagnosis. It was extremely tough diagnosis for us to accept initially, however the group and support staff have been there for us for good times and bad times.

We feel so fortunate to be able to get to know other people with similar situations and share our ups and downs.

This journey is very tough and challenging, however knowing that we are not alone and the group member and caring support staff are always available for us, makes our life bearable, sustainable and more importantly “enjoyable”. We are certain that the member of YOD really needs this support group more than ever to go through recent restrictions in our life and support each other.

Without this group, we would have known where we go to ask for appropriate help and consistent support.

'Both myself and Karin have found the support offered from the YOD Support Group amazing and absolutely essential during the last year. Whilst it has been difficult for everyone it is particularly hard on people with dementia and this forum provides both social contact and practical help to patients and carers. What I think is noteworthy is how pro-active the support workers have been, anticipating people's needs and providing prompt support on request as well'.

**If you have any suggestions for topics or guest speakers at the sessions please let me know and we can make arrangements**

## External Engagement Opportunities

The University of West London and Dr Mary O'Malley are working on a Young Onset Dementia Public Engagement Project called 'the Dementia Experts for Involvement Network for Younger People with Dementia' (DEFIN-YD) Project. The project aims to highlight different ways people affected by young onset dementia can engage with research, and we will be creating three regional public and patient involvement (PPI) forums for people to get involved with research.

They are hosting an online event on **Thursday 28th January from 1pm to 4pm** focused on engaging people living with young onset dementia in research. The event will include talks by researchers in the field, those affected by young onset dementia who have been involved in research studies, and participation opportunities.

Here is the link for people to register their interest in attending. Eventbrite link:

<https://www.eventbrite.co.uk/e/engaging-people-living-with-young-onset-dementia-in-research-tickets-128618107221>.

There is also a flyer attached to the email

## SUPPORT RESOURCES

### **Social Services – Needs Assessments and Carers Assessments – These are still happening**

A care needs assessment - or social care assessment – available from your local council, can be the vital step towards getting the help and support you need with your everyday life. **This is still happening during lockdown but probably by telephone.** 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
- Merton IAPT 020 38239063
- Richmond Wellbeing Service 020 85485550
- Kingston ICope 020 33177850
- Sutton Uplift 020 3 5134044
- Croydon IAPT 020 32284040
- Our Mind Matters Surrey 020 71834201

## Carers Centre

It is so important to register with your local carers centre so you are on their radar. Registering with them also gives you a Carers Emergency Card so if anything happens to you as a carer 72 hours emergency care will be accessed if needed.

- Wandsworth Carers 020 88771200
- Merton Carers 020 86467515
- Richmond Carers 020 88672380
- Kingston Carers 020 30312751
- Croydon Carers 020 86499339
- Surrey Carers 0303 0401234

## 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

Visit the [www.raredementiasupport.org](http://www.raredementiasupport.org) and register as a member to find specific information, receive newsletters and invitations to the specific support group webinars to hear about research opportunities, health professionals and members experiences, plus the clinical Q&A sessions. There are also carers meetings, bereaved carers meetings and interactive small group discussions on specific topics.

## 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 UK have fantastic resources and up to date news for issues regarding to the pandemic. To check which group, you are in for the vaccine

[COVID-19 vaccination first phase priority groups - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

Dementia Helpline 0800 888 6678 or [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

### Dates for the next meetings and reminder we are changing to a Thursday

#### Thursday 14<sup>th</sup> January 2021

7-8pm Members with a Diagnosis and 8-9pm Carers

#### Thursday 28<sup>th</sup> January 2021

7-8pm Members with a Diagnosis (Art Session) and 8-9pm Carers

#### Thursday 11<sup>th</sup> February 2021

7-8pm Members with a Diagnosis and 8-9pm Carers

#### Thursday 25<sup>th</sup> February 2021

7-8pm Members with a Diagnosis (Art Session) and 8-9pm Carers

**Thursday 11<sup>th</sup> March**

7-8pm Members with a Diagnosis and 8-9pm Carers

**Thursday 25<sup>th</sup> March**

7-8pm Members with a Diagnosis (Art Session) and 8-9pm Carers

\*The Art sessions are fun and informal with plenty of time to chat and socialise

If you haven't attended a Support Group meeting before, please make contact for an intro session

**Many thanks for all your help and support for making this a unique and wonderful support group. Wishing you all a Happy, Healthy 2021.**

