



Cognitive Neurology Support Services
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ST GEORGE'S YOUNG ONSET SUPPORT GROUP

Summer 2021 Newsletter

Welcome to the Summer Newsletter for the St George's Young Onset Support Group. How did we get to summer so quickly?? I hope you are enjoying the longer days and some of the occasional sunshine. The joy of the Great British Summertime!

We are finally returning to some form of normality on Monday as the restrictions are lifting. For some this is a relief with a feeling of freedom, yet for others this is an extremely cautious time. Be kind to yourselves and do whatever you feel necessary to keep safe and in your comfort zones.


We will continue to hold Zoom meetings until the hospital feels it safe to resume within the building. I will be doing monthly meetings on the last Thursday of each month, but adding in extra ones each month for people new to the group and require a bit more time for questions. We will review this in the next three months or before, if we get the go ahead. I will keep you posted on these developments.



For those of you new to the Young Onset Support Group, here is a little history of how St George's YOD Support Group started

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. It was important that this was not just for patients from St George's, but anyone affected by young onset dementia.

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 three years and we have tried to keep you all connected throughout the pandemic. Last year 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 meet monthly on the last Thursday evening 7-9pm with separate sessions 7pm for those with a diagnosis and 8pm for those caring for someone. If you have not attended a meeting before and would like more information, please email nikki@cog-neuro-support.com



Staff – who are we ??

Nikki Zimmermann Ten years of experience of Young Onset Dementia incorporating personal experience with years supporting clinics in London, including St George's, Chelsea and Westminster and the National Hospital for Neurology and Neurosurgery. I am also the Support Lead at Rare Dementia Support, Dementia Research Centre, UCL.



Elaine Eager – Carer Mentor Volunteer with heaps of experience and an absolute fountain of knowledge. Elaine is also the very valued St George's YOD Dementia Support Worker who works as part of the Cognitive Neurology Team at St George's and the vital link with the Consultants. She provides essential post diagnostic support and ongoing emotional and practical support helping people come to terms with their diagnosis and transitions throughout the journey,



SUPPORT RESOURCES

Wherever you live, we highly recommend you are in touch with your local Alzheimer's Society, Carers Centre, Age UK, and Citizens Advice Bureau. In each area these organisations are commissioned by the local authority to provide a service for you. This could be information and advice, support groups, help with form filling, information of local services and community support. Each area differs with what they will provide, but it is important to find out what they will be able to provide for YOU. These services will not know you have a diagnosis or are caring for someone as this information cannot be shared due to data protection. Registering with all these organisations is vital. You might not need them at present but being on their radar is so important to prevent a crisis in the future. Here is a quick run through of what this can mean for you:

Social Services – Needs Assessments and Carers Assessments

A care needs assessment, or social care assessment is available from your local council. This can be the vital 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 is 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.

You can apply online <https://www.gov.uk/apply-needs-assessment-social-services>

Alzheimer's Society Offices

Each area has an Alzheimer's Society Office, what they offer will vary in the different areas and this will be due to local commissioning. Most will have a Dementia Adviser who can help with information, advice and support covering a range of topics and they will know all the local amenities in the area. Some will offer educational programmes, and with restrictions lifting, some will once again offer support groups and activities. They can help liaise with the Social Services and Carers Centre to ensure you are well looked after. Contact your local office to see what is available for you

Alzheimer's Society also has an online platform finding support for you in your own area <https://dementiaconnect.alzheimers.org.uk/> just pop in your postcode.

There is also an online forum where you can talk to others online <https://forum.alzheimers.org.uk/>

- 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

CounsellingEveryone needs a little help sometimes

Whether you have a diagnosis yourself and are struggling with the impact this is going to have on your life. Or if you are caring for a loved one who has a diagnosis and things are slowly changing, the dynamics in relationships can be very upsetting and transitions are difficult. Counselling is a helpful way to accepting these changes.

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. These conditions are treated using a variety of therapeutic techniques, including cognitive behavioural therapy (CBT), interpersonal therapy (IPT) and couples therapy. It is a free service, and you can self refer without going to see your GP. Although if you are feeling a bit low, I would advise speaking to your GP as it is very important they know how you are feeling and how you are coping. Please be aware there is often a waiting list:

- Talk Wandsworth 0203 513626
 - Merton IAPT 0203 8239063
- Richmond Wellbeing Service 0208 5485550
 - Kingston ICope 0203 3177850
 - Sutton Uplift 0203 5134044
 - Croydon IAPT 0203 2284040
- Mind Matters Surrey 0300 330 5450

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 meaning if anything happens to you as a carer 72 hours emergency care will be accessed if needed. The Carers Centre can offer you advice and support, provide respite and services to look after you as a Carer. It is so important looking after yourself as a Carer, if you don't, you will burn out very quickly and you won't be able to care for your loved one to your best ability. The saying '*You can't pour from an empty cup*' comes to mind. Practical support is very important of course, but emotional support is equally important.

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

Dementia UK

Admiral Nurses can provide a specialist listening ear for families when things get challenging or difficult. There is a Dementia Helpline on 0800 888 6678 or helpline@dementiauk.org

Rare Dementia Support (RDS)

Rare Dementia Support (RDS) is a world-leading, UK-based service led by the UCL Dementia Research Centre (DRC). The aim being to empower, guide and inform people living with a rare dementia diagnosis and those who care about them. There are 7 diagnosis specific dedicated support groups that bring people together to share their experiences and a specialist Direct Support Team, who are available by email and telephone contact@raredementiasupport.org

RDS covers many of the dementias associated with young onset, so there will be a group available for everyone

- Frontotemporal Dementia,
- Primary Progressive Aphasia, including Semantic dementia. Progressive non-Fluent Aphasia and Logopenic Aphasia
- Posterior Cortical Atrophy,
- Dementia with Lewy's Bodies,
- Familial (genetic) Frontotemporal Dementia
- Familial Alzheimer's disease
- Young Onset Alzheimer's disease

Visit the www.raredementiasupport.org and register free to become a member to find specific information. Once on the mailing list you will receive newsletters and invitations to the specific support group webinars to hear about research opportunities, health professionals and members experiences, plus clinical Q&A sessions. There are also Carers meetings, Bereaved Carers meetings and interactive small group discussions on specific topics. Have a look at past meetings on this link

<https://www.youtube.com/channel/UCuVA3iffOcwz04qBkjZgKqg>

You may recognise the wonderful Elaine in conversation in the most recent PPA meeting: [\(591\) PPA Support Group Webinar - 23rd June 2021 - YouTube](#)

Dates for the St George's Young Onset Support Group

The Zoom meetings are 7pm -9pm

7-8pm is a discussion group for those with a diagnosis

8-9pm is for informative presentations and peer support for carers

Thursday 29th July

Thursday 26th August

Thursday 28th September

Recent Information sessions have included:

- Knowing your Health Professionals
 - Contenance Problems
 - Advanced Care Planning
- Accessing Care at Home Service

Please contact nikki@cog-neuro-support.com with any suggestions for topics



For new members we will be holding Taster sessions on the following dates

Thursday 15th July

Thursday 12th August

Thursday 15th September

Thursday 24th June

Please contact nikki@cog-neuro-support.com

Many thanks for all your help and support for making this a unique and wonderful support group.

