



Cognitive Neurology Support Services
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ST GEORGE'S YOUNG ONSET SUPPORT GROUP
December 2021 Newsletter



Welcome to the Christmas Newsletter for the St George's Young Onset Support Group. I really can't believe we are here at the end of 2021. Another year severely disrupted by Coronavirus. As I sit here composing this letter, we have the highest daily figure of reported COVID cases

since the pandemic began with 119,789 cases. I, like so many others have friends and family members testing positive and isolating, luckily many have mild symptoms due to triple vaccinations. But we are ending the year with huge amounts of concern and apprehensive about what January will bring. Some hospital clinics have already cancelled face to face appointments and will be returning once again to Zoom and telephone appointments. I will try and keep you updated here.

As I look back on the year, I remember the pleasant walks some of us shared at Morden Hall Park and how wonderful it was when we finally got to hold the meetings live again in St George's, albeit with a restricted number. We managed well on Zoom and we will I am sure manage again on Zoom for a little while, but I do hope we will be returning to live meetings again in Springtime.

It really is going to be a matter of watch this space though, as nobody really knows yet.

A huge loss this year was seeing Elaine leave her post as Young Onset Dementia Support Worker. This has left a huge gap as I am sure many of you are feeling. Moira and Helen. The Dementia Nurses are trying hard to support members, but as you can imagine Elaine had worked so hard during her two years and made such a difference in many of your lives, this along with Elaine's lovely smiley face is sorely missed. Elaine is still joining me at the Support Group monthly meetings and is such an asset to the group. Any support needs for St George's will be provided by Moira and Helen and the Dementia Advisers and Support Workers at the local Alzheimer's Society. These are all commissioned locally and are there to provide information and advice. You can also source local support to you by popping your postcode into the search in Dementia Connect

[Alzheimer's Society - United Against Dementia \(alzheimers.org.uk\)](https://www.alzheimers.org.uk)

Find local services near you

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.



Staff – who are we ??

Nikki Zimmermann - Over ten years of experience of Young Onset Dementia incorporating personal experience with professional 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 where I lead a team providing 1:1 Support, small group support and large support webinars and annual seminars for different types of rare dementia.

Elaine Eager – Carer Mentor with heaps of experience and an absolute fountain of knowledge. Elaine was previously the very valued St George's Young Onset Dementia Support Worker who worked as part of the Cognitive Neurology Team at St George's Hospital. Elaine will be assisting at meetings with emotional and practical support, helping people and carers come to terms with the diagnosis and adapting.

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. It is also advisable to register as a carer with your GP to ensure you can get extra time in the appointments and so they can share information.

Here is a quick run through if 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>

It is always good to have a new assessment when circumstances change, and when you feel there are some new changes as these will identify new needs.

In many areas you can start the assessment online by answering a few questions. I would imagine over the next few months most assessments will be carried out over the telephone due to COVID restrictions again.

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. They can help liaise with the Social Services and Carers Centre to ensure you get the assessments and benefits required. 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
- richmondservices@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

Over the festive period Call

Supporter Care team can be reached on 0330 333 0804

8am to 10pm every day (except Christmas Day).

For Dementia support call Dementia Connect support line on 0333 150 3456

Phone support is available most days, with a restricted service over the Christmas period.

CounsellingEveryone needs a little help sometimes and this can happen at Christmas time

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

Christmas Opening times – everyday apart from Christmas day

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 nonFluent 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 monthly Peer Support Zoom groups for Carers and separate ones for loved ones living with a rare dementia. These groups are specific to the subtype and helps to introduce you to others in similar situations



Dates for the St George's Young Onset Support Group – 7pm -9pm

- **At present I can't say if they will be Zoom or live, but I will let you know as soon as possible**

Thurs 27th January

Thurs 24th February

Thurs 31st March

Thurs 28th April

Thurs 26th May

Thurs 30th June

Thurs 28th July

If there are topics you would like to cover over the next 7 months, please do let me know as the sessions are shaped by your needs

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

Finally, thoughts for the dear friends we have lost this year, such treasured members of the support group. Our thoughts and prayers are with the families at this very difficult time

Roy Higgins

Ron Elam

Kuldip Rihal

RIP

