



ST GEORGE'S YOUNG ONSET SUPPORT GROUP Springtime 2022 Newsletter



Welcome to the Springtime Newsletter for the St George's Young Onset Support Group. It is so wonderful to see the days getting longer, the flowers in the parks and gardens blooming, the trees coming back to life especially my favourite, Cherry Blossom. I hope you have all been enjoying the milder days when we have them and looking forward to the temperature rising. As Easter appears it feels like that summer is not far away and we all appreciate the longer summer evenings and hope it will encourage more of you to attend our monthly evening support group meetings.

I feel we have come a long way from the Zoom meetings we were limited to last year and it has been delightful being able to meet up again. We have welcomed lots of new people and it's wonderful watching new friendships develop. Please remember this is your group and we are

very lucky to have a specific YOD group attached to the Hospital, and generously funded by the St George's Charity. Please do come along and take advantage of it, there are very few around and if you don't use it, we may lose it!

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.



St George's Young Onset Support Group

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. Elaine also

works for Wigmore Hall providing support for the Music for Life programme in Care Homes

The Support Group meetings

The Support Group meets on the last Thursday of each month at 7pm in the John Parker Lecture Theatre in the Atkinson Morley Wing. It's a friendly and welcoming group there to facilitate peer support, provide information and advice and to bring along a variety of professionals to enhance wellbeing, give professional advice and meet the needs of the group

So far this year we have had expert advice from Trish O'Hara, Rights and Entitlements Officer at RDS, taken part in some Research Poetry with Prof Paul Camic, UCL and we have some fantastic evenings coming up including a music session from The Royal Academy, An evening of the special St George's YOD Poem, a presentation from Join Dementia Research and an evening on activities and cultural engagement. If you have any requests or suggestions please email nikki.zimmermann@nhs.net

Here is a little taster of the Poetry Eveing with Bill enjoying his favourite poem



Mr. Nobody

I know a funny little man,
As quiet as a mouse,

Who does the mischief
that is done
In everybody's house!
There's no one ever
sees his face,

And yet we all agree
That every plate we break was
cracked
By Mr. Nobody.



And from Gill and Dave



The London Breed - Benjamin Zephaniah in Too Black Too Strong

*I love dis polluted place
Where pop stars come to live their dreams
Here ravers come for drum and bass
And politicians plan their schemes,
The music of the world is here
Dis city can play any song
They came to here from everywhere
Tis they made dis city strong.*

*A world of food displayed on streets
Where all the world can come and dine
On meals that end with bitter sweets
And cultures melt and intertwine,
Two hundred languages give voice
To fifteen thousand changing years
And all religions can rejoice
With exiled souls and pioneers.*

*I love dis overcrowded place
Where old buildings mark men and time
And new buildings all seem to race
Up to a cloudy dank skyline,
Too many cars mean dire air
Too many guns mean danger*

*Too many drugs mean be aware
Of strange gifts from a stranger.*

*It's so cool when the heat is on
And when it's cool it's so wicked
We just keep melting into one
Just like the tribes before us did,
I love dis concrete jungle still
With all its sirens and its speed
The people here united will
Create a kind of London breed.*

SUPPORT RESOURCES

Support needs for St George's is provided by Moira and the Nursing Team and they refer out to the local Dementia Advisers and Support Workers at the 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 \(alzheimers.org.uk\)](http://alzheimers.org.uk)

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.

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

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

CounsellingEveryone needs a little help

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 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. The live seminars will start again this month.

Dates for the St George's Young Onset Support Group

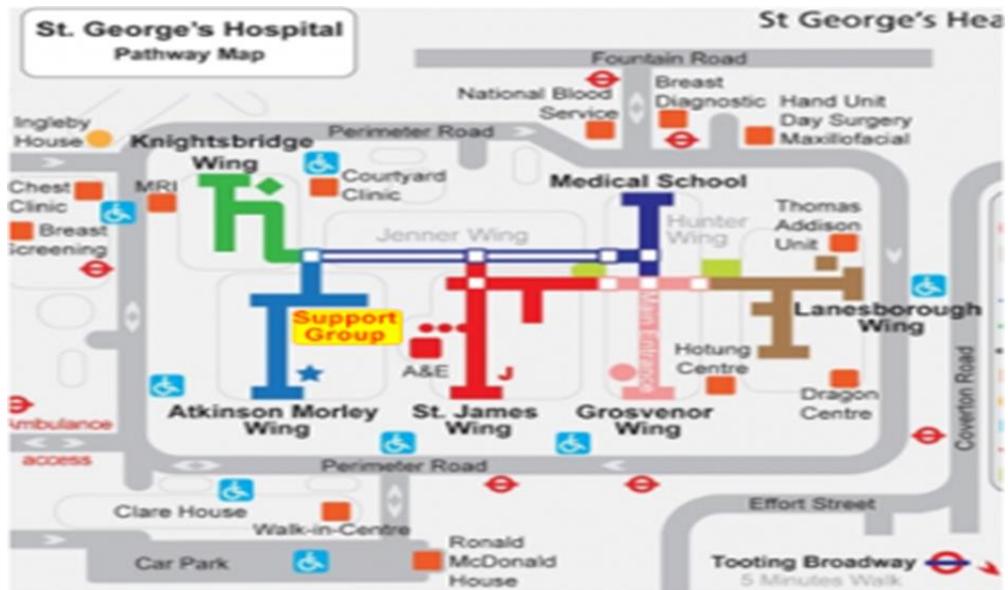
The last Thursday of each month 7pm - 9pm

Thurs 28th April

Thurs 26th May

Thurs 30th June

Thurs 28th July



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



Contact: nikki.zimmermann@nhs.net

