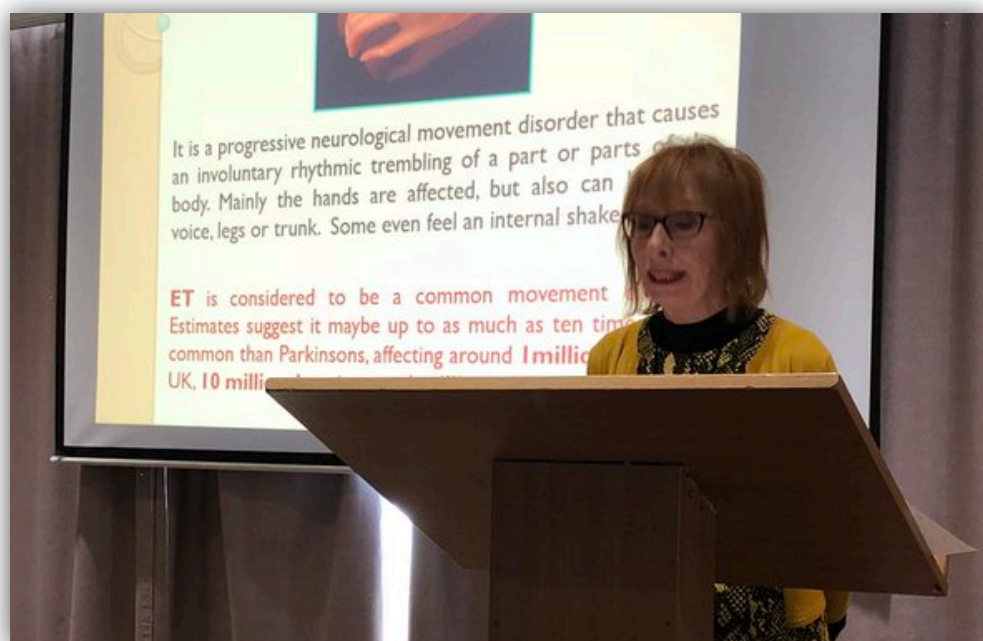


Essential Tremor Awareness Day

Holiday Inn, Sutton, SM1 2RF

March 9th 2019



The proceedings were hosted by Jackie Farrell (NTF support group coordinator).

A warm welcome was expressed to the Mayor & Mayoress of Sutton Steve and Pauline Cook. The mayor then gave an opening speech and said that six months ago he didn't know the condition of essential tremor existed until he met Jackie at another local event and visited the NTF information table.



Funded by Sutton Neighbourhood Grant

The event attracted over 70 visitors. Jackie opened her Essential Tremor presentation by identifying those present who had essential tremor. Some had never met another with ET before and had previously felt isolated & alone. The day offered people the opportunity to share experiences & realize others had similar too. Sutton Shakers support group were delighted to welcome new members. Visitors may have arrived as strangers, but they left as friends!



Sharing a joke. Meetings can be fun too!

GyroGear

Stuart Clarke & Gordon McCabe from GyroGear gave a presentation about GyroGlove, a device being developed that will help stabilize hand tremors. More information: gyrogear.co



Stuart Clarke



A video was shown of a prototype Gryoglove featured on the BBC One Show in 2018.

Tips

A few helpful items discussed during the presentation.



Sunflower Hidden disabilities
Lanyard available at UK airports



<https://tfl.gov.uk/transport-accessibility/please-offer-me-a-seat>

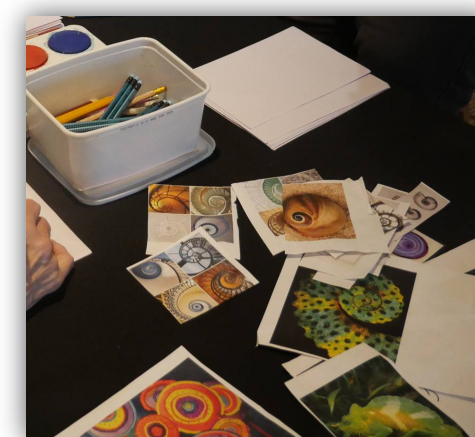
Handsteady mug
handsteady.com/



www.safe-sip.com

Draw with Jo

Local artist Jo Sharpe guiding Mindful drawing. The theme was spirals



ET can affect any age from birth



For some it may come as a surprise to learn the disorder can also affect children. Estimated 5% of cases are in the childhood population. Also 60% of cases are hereditary as in the case of one young mother with ET. Heather came along on the day with her 4yr old son who also has the disorder. She explained a few of the issues he has at school. That is no disrespect to the teachers but simply the fact there is not enough awareness in the education profession. Incidentally he was really happy with his colouring picture!

Young adults

It was good to welcome young adults and highlight their difficulties coping with tremors.

"Having a progressive neurological disorder in your 20s is terrifying. From the loss of independence to trying to navigate relationships, it is a constant struggle to remain positive and to hold on to dignity in day-to-day life. What's more, the thing that makes it so much harder is when no-one you meet has ever heard of the condition that dominates your life.
Samantha"



"Hi my name is Hayley Brook-Bell and I have Essential Tremor. I first noticed my hands were shaking at the age of 18. I finished college with my qualifications for Childcare and Education Cache, but I had a really difficult time getting employment as I was always deemed too nervous at interviews as when reading a book my hands would shake. I am 28 this year and the tremor has progressed to my neck, voicebox and legs. I have "Young People Living With Essential Tremor 18-30" FB page and discovered that more and more people are being diagnosed at a younger age. When I first attended a National Tremor Foundation meeting it was quite daunting as there was nobody there that was young. Jackie has been an inspiration and a great help to me. She has worked to get people together of all ages that have essential tremor. **Hayley**"



Hayley

Who else does ET affect?

"ET not only affects those with the disorder, but also close family members and friends too. It can sometimes make them feel slightly helpless not knowing how to approach or help the person concerned. So they are also welcome at support groups to meet others in the same position. We appreciate all you do to help make our lives easier. I know without the support of my husband Tony, I'd not be able to take on the activities I do. **Jackie.**"

Sutton Shakers Tremor Support Group

Support groups are a good way to meet others with ET.
For more information & next meeting, please contact:

Jackie Farrell jackie@tremor.org.uk

Helpers

"An event like this cannot happen without many helpers & teamwork. Big thanks to everyone involved who helped in some way to bring about an amazing day. **Jackie Farrell**"



Katherine Phillips from Oxford support group looking after visitors throughout the day.



NTF Support group leaders on hand to answer any questions. L to R Jamie Goodchild (Cambridge), Katherine Phillips (Oxford), Jackie Farrell (Sutton & Surrey), Larz Jackson (Nuneaton)

Sutton Council

Thanks to The Mayor & Mayoress of Sutton, Councillors Nali Patel, Catherine Gray & Lily Bande (see photo) Also Cllrs Marlene Heron & Jane Pascoe. We appreciate your supporting our initiative from the beginning and by attending our event. We are grateful to all at Sutton Council for their continued support in helping raise awareness of Essential Tremor.

Sutton Local Committee was proud to fund the event to raise awareness of Essential Tremor which was well attended and very informative. Jackie came along to the Local Committee meeting to report back on how the day went and it gave her another opportunity to get the message out. People were staggered that ET is more prevalent than Parkinson's Disease and is sometimes misdiagnosed by GP's. I am sure that through these two opportunities a stronger support group for ET sufferers and their families will emerge and Sutton Council is grateful to Jackie for her tireless efforts.

Cllr. Marlene Heron Chair Sutton Local Committee

"A big thank you from all the trustees at the NTF to everyone involved in instigating, organising & putting this successful event together."

Kevin Harfoot, NTF Chairman



I met this amazing lady during Sutton Police open day last year. I was impressed by the way she was talking about Essential Tremor and the effect it has in everyday life. I invited her to exhibit at the Wallington Wellbeing Day where she got the opportunity to talk to many people. We spoke about the ET Awareness day to be held at Holiday Inn March 9th 2019 when I promised to assist in advertising the event. I salute her for her courage proving that Disability Is not inability.

Cllr Nali Patel, LB Sutton Older People's Champion

Essential Tremor Awareness Day success was far reaching. Jackie is continuing with her efforts to raise awareness"

Councillor Lily Bande

Report by Jackie Farrell, NTF support group coordinator.