

Connexions

July 2024
Bulletin No.5

Essex
Neurology
Network



This news bulletin brings together news and information about local Essex NHS Neurology services, support groups for patients, their families & carers, and local and national initiatives and research, which we hope you will share with colleagues, family and friends

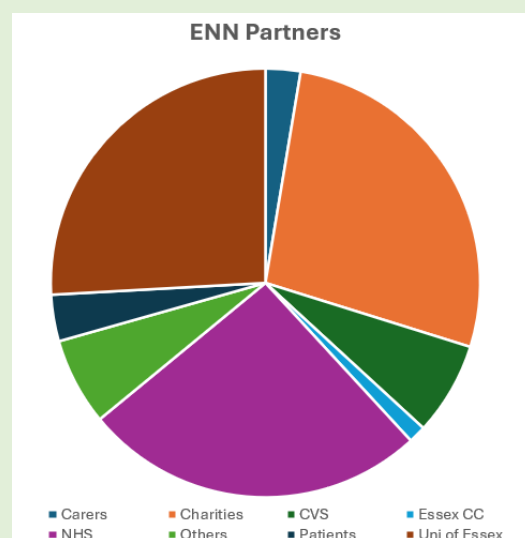
Essex Neurology Network Celebrates Just a year ago, we relaunched the Network. And what an amazing year it has been! We have so much to celebrate that we have achieved in that short time! Originally founded in 2008, the Network has grown this year from around 50 to nearly 250 people and organisations, all of them interested in neurological conditions! Many of them are professionals or from charities or are involved with the University of Essex, whilst just a few are patients and carers, whose lived experiences are so very important. We now need to encourage more people with neurological conditions to join.

During the past year, we have had regular Open meetings, with talks about carers, insight into a new resource book for disabled people called 'Shaping My Future', an insight into the new Health, Wellbeing & Care Hub at the University and recently we have learnt about the work of a hospice caring for patients with neurological conditions.

We have established a webpage, created these news bulletins, come under the wing of a charity and become a member of the Neurological Alliance. We have made new friends and contacts in every part of the county and beyond.

Our mission is to work together to ensure the best services and support for all Essex patients with neurological conditions, along with their families and carers, so that they have access to high quality resources and the support they need to enable them to live an active and fulfilled life.

Anyone interested can join ENN, whether you are someone with a neurological condition, a family member, a carer or support organisation, or are part of any NHS service that supports people with neurological conditions. **Membership is free – register your interest NOW** with our secretary and help us make a difference: essexneuronetwork@gmail.com We have great plans for the coming year!



Essex Neurology Network is excited to announce that we are now a member of the Neurological Alliance, which is England's leading coalition of organisations and professional bodies supporting people with neurological conditions.

Over 90 organisations work together to ensure that every person affected by a neurological condition can access the right treatment, care and support at the right time. They link with other UK Alliances to collect, analyse and share the evidence needed to create real change throughout the UK and improve services for everyone living with a neurological condition.

They harness the energy and passion of the neurological community to ensure public policy in health reflects the realities of living with a neurological condition. Together they are a strong voice for change. Working together for the one in six people – adults and children in the UK who live with a neurological condition, support them and their carers, health care professionals, not-for-profit, charity or support groups and policy makers.

We are proud to be members of the Alliance and look forward to working in partnership with them in the near future. For more information about the Alliance see: [Home – The Neurological Alliance \(neural.org.uk\)](http://neural.org.uk)



Call on your next **MP** to be a **#NeuroChampion** in the next Parliament.

#BackThe1in6

The Neurological Alliance has launched its #NeuroChampion campaign calling on prospective parliamentary candidates (PPCs) to speak up for people affected by neurological conditions in the next Parliament.

Neurological conditions affect one in six people in the UK but too often they can't access the services and support they need.

Your next Member of Parliament (MP) can help change this by becoming a #NeuroChampion and speaking up for the neurological community in Parliament.

Use this link to access the template email on the Neurological Alliance webpage. It is very easy and quick to use and will go straight to your candidates: <https://bit.ly/NeuroChampion>

Please share your support for the #NeuroChampion campaign on social media and with people you know. **Together we're stronger.** For further information see the [#NeuroChampion Engagement Pack](#)


Take part in ME research study

The ME Association is funding a study led by Prof Sarah Tyson of University of Manchester (who also has ME) to develop a clinical assessment toolkit in collaboration with people with ME and clinicians in ME services. It will use gold-standard techniques to develop a range of patient-reported outcome measures (PROMs).

Prof Tyson's work in other long-term disabling conditions has shown that PROMs will be useful for PwME and clinical services to evaluate and monitor the nature and severity of PwME's symptoms and activity levels; identify patients' needs (which forms the basis of goal setting and treatment planning), and to monitor progress. There will also be a satisfaction measure, which contributes to service development.

If you have any questions, or would like further information, please contact sarah.tyson@manchester.ac.uk or to take the survey:

[Qualtrics Survey | Qualtrics Experience Management \(manchester.ac.uk\)](#)

**Essex
Neurology
Network** 

Our Carers' Compendium has at long last been posted on our website page. There is information for both paid and unpaid carers, about support organisations, finding a carer, and relevant articles and general information about and for carers and for those needing care.

Whilst we have tried to include as much as we could, there is always more that could be added, so it is planned to update it annually. We hope that you will find it is a useful collection of information for and about carers in Essex. See bottom of page at [Essex Neurology Network | University of Essex](#)



Thank You Day Sunday July 7th 2024 Every year, Thank You Day brings together millions of people across the UK to celebrate and give thanks to those that go above and beyond for us. It is an opportunity to thank the people who go the extra mile for us!

For more information see: [Members of the public - Thank You Day](#)



Autistica is the UK's leading autism research and campaigning charity. Our mission is to create breakthroughs that enable all autistic people to live happier, healthier, longer lives. We do this by funding research, shaping policy and working with autistic people to make more of a difference.

Mental health struggles are common in autistic people, often impacting their daily lives in profoundly negative ways. With 80% of autistic adults experiencing mental health challenges at some point in their lives, we urgently need to improve understanding and support.

Anxiety disorders are just one of the conditions that stop many autistic people from going to school, attending important doctor's appointments and leaving their homes. However, research is making strides in understanding the unique aspects of anxiety in autistic people. By learning more we can develop better-tailored supports that address individual needs more effectively.

For more information see: [Home - Autism | Autistica](#)



Specialist Palliative and End of Life Care Skills – Neurological Study Day at St Luke's Hospice, Basildon

St Luke's Hospice is a local charity providing compassionate care to people whose illnesses are no longer curable. We promote dignity in dying and empower people to make the choices they want, from the moment they are diagnosed.

Kelly Watts, Lead Clinical Skills Facilitator at the hospice gave a stimulating talk to ENN Members in May. Staff had requested learning about neurological conditions, as they had started to see more and more patients with neurological conditions and felt that they were not always equipped to deal with patient and loved one's care needs or requests. Clinician's attended the study day, with 13 internal staff and 15 external staff attending from GP Surgeries, other Hospices and Community Services.

They invited varied external speakers, who are experts in the field of neurological conditions and have knowledge or experience of End of Life. These included a carer whose brother has Huntington's Disease, clinical nurse specialists for Huntington's Disease and Motor Neurone Disease, a representative from the Marillac Care Centre in Brentwood, which provides specialist care and treatment for residents with complex neurological conditions, and a member of the North Essex Environmental Controls – Adaptive Technology Team. The Experts by Experience really highlighted the struggles of patients and carers during their journeys and the varied speakers spoke of differences in neurological conditions and care.

The talk inspired many questions from those ENN members attending the talk and enabled us to think about the possibilities for improving communications between all service providers and patients with neurological conditions & with their carers.



MS-UK is a national charity that provides support to anyone affected by multiple sclerosis to live healthier and happier lives. Our services include:

- National [helpline](#) - providing MS-related information and emotional support over the phone, WhatsApp, webchat and email.

- Online and printed information through our [website](#), [booklets](#) and [magazine](#)
- Weekly online [activities](#) including exercise, chair yoga, Qi Gong & Guided meditation classes
- Courses such as [mindfulness](#) and Healthy Habits
- [Peer support](#) – online friendship groups for people with shared interests
- Expert-led [online information sessions](#) on many MS related topics
- [eLearning](#) and [MS Awareness training sessions](#) for professionals

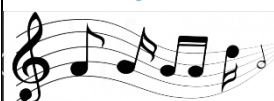
Please feel free to contact us on 0800 783 0518 if you would like to find out any more about any of our services. [Home | MS-UK | Supporting your multiple sclerosis journey](#)

At our May meeting about the New Hub, we received a question about how stress is considered and what tools are used to reduce stress in patients. Our chairman responded:

The issue of how we consider stress and disorder – and stress management – is high in my mind in all of my clinical work. We have an aphorism about the inseparability of cognitive, physical and emotional experiences and the interactions between them. So recognising where stress fits into this (as a cognitive burden) (it's harder to think when stressed), as a physiological response (think heart rate, gut, perspiration), and emotional (how it feels to be stressed) is precisely the conversation I'd have with any patient I am assessing – or more precisely when I'm supervising students in learning to assess and work with individuals. And so, when I think about being holistic in our approach, it's this idea of the whole person's life that I'm trying to understand, and where their health condition fits into this. The tools used to help then depend on the specific challenges e.g. cognitive assistive technology, physical relaxation exercises, or mind/emotional relaxation/distraction and self-awareness raising mixed in with helping people understand their situation better, is a typical way of thinking about your question.

Professor Andrew Bateman

Musicophilia: Tales of Music and the Brain



“Music can lift us out of depression or move us to tears - it is a remedy, a tonic, orange juice for the ear. But for many neurological patients, music is even more - it can provide access, even when no medication can, to movement, to speech, to life.

Music therapy as a tool of great power in many neurological disorders - Parkinson's and Alzheimer's - because of its unique capacity to organize or reorganize cerebral function when it has been damaged. The power of music to integrate and cure. . . is quite fundamental. It is the profoundest nonchemical medication.”

Oliver Sacks was a pioneer in promoting music to help with brain injuries and conditions. His book, **Musicophilia: Tales of Music and the Brain**, explores the place music occupies in the brain and how it affects the human condition. Whilst his theories may not be recent, awareness of the benefits of music is currently very much accepted as the way forward to help those afflicted with brain conditions.

Oliver Sacks - British neurologist, naturalist, historian of science, and writer 1933 – 1975



CHARTERED
SOCIETY
OF
PHYSIOTHERAPY

The Community Rehabilitation Alliance

The **CRA** is a partnership of more than 50 charities and professional bodies, who are all committed to improving commissioning, planning and delivery of rehabilitation.

The importance of rehabilitation and recovery

The demand for high-quality rehabilitation and recovery services has never been greater. With more people living longer, often with multiple long-term conditions, rehab and recovery services are vital in managing and maintaining health. But we know there isn't enough provision to meet demand, and the covid pandemic has only made the situation worse.

While there are excellent examples of rehabilitation services, they are not consistently available. Services are often not joined up between acute, residential and home settings, so people can easily be lost in the system. Where people can access services, they often have to wait too long, making rehabilitation more difficult or less effective. There is also poor awareness of the benefits of rehabilitation among the public, healthcare professionals and commissioners.

The impact of quality rehab and recovery

Rehabilitation and recovery enable people to regain life skills, return to work, maintain mobility and manage symptoms. It can slow disease progression and optimise the effectiveness of treatments. It is also critical to prevention. It can reduce fragility fractures, the risk of falls and the development of long-term conditions. All of which helps to prevent readmission to acute services, reduces social care needs and helps to prevent disability, with its impact on people's mental and physical health.

<https://www.csp.org.uk>



Encephalitis International
The brain inflammation non-profit

Encephalitis 2024!
2nd – 3rd December
Royal College of Physicians Conference
London / Virtually

Encephalitis 2024 is dedicated exclusively to encephalitis and covers epidemiology, pathogenesis, diagnosis, treatment and rehabilitation in both children and adults, covering both infectious and autoimmune aetiologies.

There will be cutting-edge insights from global leaders in the field of brain inflammation covering hot topics, critical research questions, and approaches to the key clinical challenges informed by the latest research.

ENCEPHALITIS 2024 is an excellent forum for physicians, scientists, researchers, and healthcare professionals to exchange ideas, knowledge and clinical experience relating to encephalitis. You can join us in person at the Royal College of Physicians, London or virtually, via the on-line Conference Platform.

[Registration is now open!](#) [Call for abstracts is now open!](#)

Covid Research

New research reveals that more than a quarter of people with a Covid infection develop Long Covid, and will also experience brain fog, whilst one in three to four will develop anxiety or depression. The findings of the study, published in the journal *General Hospital Psychiatry*, suggest that full Covid vaccination makes sufferers four times less likely to have brain fog – a term used to describe symptoms including poor concentration, feeling confused and cognitive impairment.

The study reviewed 17 studies from around the world involving more than 40,000 Long COVID patients. It was carried out in collaboration with the STIMULATE-ICP project, which is a £6.8 million NIHR-funded national research project led by University College London.

Lead author, Professor Christina van der Feltz-Cornelis, Chair of Psychiatry and Epidemiology at the Department of Health Sciences and at the University of York and Hull Medical School (HYMS), said: “With so many people suffering from the severe effects of this condition, our study clearly points to the need for greater support, in addition to sustained vaccination programmes. We are very lucky to be one of the only countries to have dedicated Long Covid centres, but we need more joined-up treatment of the mental and physical symptoms of the condition and greater resources for effective treatments, rehabilitation and occupational therapy so that people are able to recover and avoid losing their careers and livelihoods.”

University of York Press Release, 30 April 2024

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The Impact of Covid on Death, Dying and Bereavement

During Covid, South Woodham Ferrers Health & Social Care Group managed and delivered voluntary health and welfare essential support in the SWF area. During the initial and subsequent lockdowns, we saw the devastating impact it had on people who were dying, then died, and on those left bereaved. The arrangements were brutal when compared to ‘the norm’.

Memories may dim, and though understandably, we want to move on, some who suffered continue to be stuck with dreadful memories and effects. Our aim has been to document people’s observations, which can remind us of what went on, reflect upon what happened, consider the effects it had and continues to have, and may stimulate consideration of what can be learnt and done differently when the next pandemic strikes, as it surely will.

This 40-minute film describes the experience of a widow whose husband died from Covid in March 2020. Alongside that, we also have the experiences of a hospital chaplain, a funeral director, a ward sister, a medical director, a community nurse, and a GP. The film is being launched in June 2024 and will be available freely for use in whole or part in any work and activities.

We ask users to credit both South Woodham Ferrers Health & Social Care Group and Two Cubed Creative, who hold the copyright and we politely ask that you also make contact with us prior to publication and/or use of the film, by emailing swfhealthsocial@outlook.com

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Looking beyond the NHS Constitution to a meaningful Patient Promise

The Government has launched a consultation on the NHS Constitution, which sets out your rights as an NHS patient. Read why it's important to have your say on the constitution. Find out more about the proposals, visit [**NHS Constitution: 10 year review**](#). The public consultation closes at 11:59 PM on June 25, 2024.

Have your say on the NHS Constitution. <https://consultations.dhsc.gov.uk/en/660d21db9ecc4223dd0174bf>

Latest Research: [Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021 - The Lancet Neurology](#) Published March 24th 2024



The University of Essex hosts cross-departmental 'Brown Bag' meetings.

What is a Brown Bag meeting? An informal and friendly opportunity to meet all sorts of people interested in

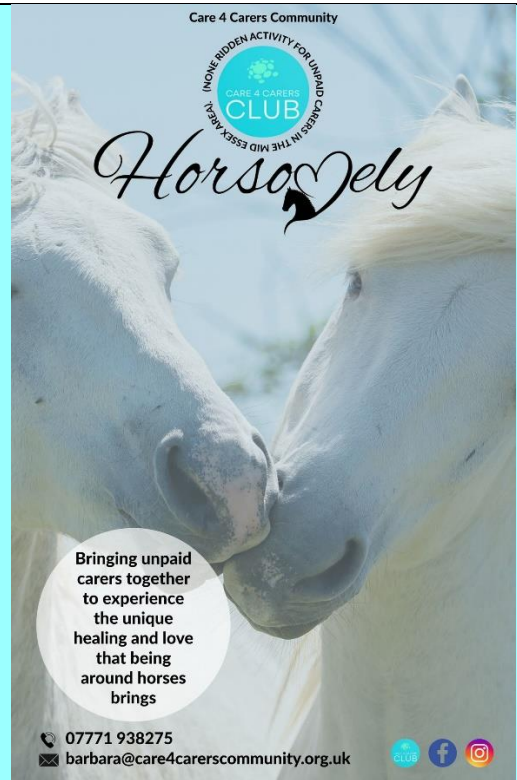
neurorehabilitation research, from academic researchers to patients and the public, and health and social care professionals. We collaborate on a Padlet to share information, contacts and opportunities: <https://padlet.com/katiechadd8/uo-neurorehab-research-brown-bags-b8sww61e47aa22a8>

Coming sessions:

- Wednesday 24 July, 4-5pm
- Thursday 22 August, 4-5pm

Please register online:

<https://forms.office.com/e/KfpMcjPyPf>
or email Katie Chadd on katie.chadd@essex.ac.uk



The intensive care patient support charity.

Critical illness can be a traumatic experience. We want to make sure surviving isn't.


For patients and relatives, the experience of critical illness is a traumatic experience which people who have not experienced it cannot understand.

Recovery doesn't end when we leave the ICU or even the hospital. It's only just beginning. To get back to a normal life we need support, rehabilitation and patience because it will take time, often a year or longer, to overcome the physical, emotional and cognitive consequences of critical illness. However, you're not alone.

The people that work in the ICU do an amazing job, but even when patients are on the road to recovery they still have a long way to go before they're fully better. Depending on how ill the patient has been, recovery can take a year or more.

Knowing what might lie ahead, and also that you're not alone in what you're going through, can be a great help for both patients and relatives. <https://icusteps.org/>

True stories

On a trip to a London Hospital appointment recently, my partner, who is in a wheelchair, needed to pay a visit to the disabled toilet at the main line station. Of the three cubicles, one was disgustingly filthy & unuseable, the second was out of order and the third one engaged. 

After waiting an interminable time, eventually the door opened slowly and out came a little, elderly homeless gentleman, carrying three huge black dustbin sacks. Needs must, so we took a deep breath and in we went! After we came out and were waiting for the lift, he appeared again to point us in the direction of another much cleaner toilet in a nearby pub. 'But you'll have to pay', he said! We shall think of him next time.

If you have a story about how someone went out of their way to do something special to help you, or someone with a neurological condition that you know, then please send it to:

essexneuronetwork@gmail.com

Short articles or adverts about neurological conditions, services or support organisations are welcome. The next deadline is: August 1st.

Send to essexneuronetwork@gmail.com
