

Connexions

January 2024
Bulletin No.2

Essex
Neurology
Network



Website: [Essex Neurology Network | University of Essex](#) email: essexneuronetwork@gmail.com

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

Essex Neurology Network is an umbrella organisation that brings together local Essex NHS neurology service providers, national & local support organisations, and researchers, as well as people, families and carers affected by neurological conditions. We work together to ensure the best services and support for all Essex patients, 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.

We now have a **webpage on the University of Essex's website**, along with our **QR code** – see head of page. We also have a **newly designed poster** (see attached document).

We invite you to join our membership & support our aims! Please support the work we do by spreading the word about the Network and **by printing off a copy of the poster and displaying it somewhere** that staff or people with neurological conditions and their families & carers may see it.

Anyone interested in our aims is welcome to join - ENN Membership is free and enables people to attend our meetings, receive our regular news bulletins and to be involved in our projects – **register your interest NOW** with our secretary.



Care for Carers
Supporting those who care for others

Next Essex Neurology Network Meeting

Title: 'Carers and Personal Assistant Retention'

A talk by Barbara Carr from Essex Care4Carers Club

about the valuable work that carers do and issues associated with caring.

Thursday January 18th 2024 at 4pm Everyone welcome!

If you would like to join us at the University of Essex, Colchester or to take part online – then please contact essexneuronetwork@gmail.com for details or the zoom link.

Essex Neurology Network is pleased to be working in partnership with the **University of Essex**, which is based on their Colchester Campus. It specialises in applied, multi-disciplinary research that addresses local, national and international issues relating to health and social care policy and practice, and other related fields.

The University is recognised internationally for its globally important research. Its researchers are daring, visionary thinkers, constantly asking difficult questions and providing answers that shape thinking and influences policy. At Essex, they believe good health and wellbeing for all is achievable by better addressing the multiple root causes of ill-health and by taking a collaborative, interdisciplinary and global approach.

Professor Andrew Bateman, School of Health and Social Care, recently became chair of the Essex Neurology Network. He is experienced in research and clinical rehabilitation and involved with ambitious plans in opening up public-facing clinics and services to even more people, including a state-of-the-art Health, Wellbeing and Care Hub, a centre of excellence in health and care-related research and workforce development, opening at the University this Spring.



WE NEED YOUR HELP! If you are enthusiastic and committed to our aims, then you might like to help plan future events, talks and projects. We are seeking just a few interested people to join our small friendly committee, which meets occasionally online to manage the affairs of the Essex Neurology Network. We need experienced people, including patients, committed to seeking improvements in neurological care and support. If you are interested or would like to know more then email our secretary.

MSE Virtual Views is a new engagement platform that gives people in the Mid & South Essex area a simple way to share their experiences and views about health and care services. The information that everyone gives them remains anonymous but gives good information about gaps in provision for particular groups within our communities and possible improvements the local NHS could make. They would love it if you joined them for online discussions of future health and care through MSE Virtual Views. You can sign up by clicking this link: <https://virtualviews.midandsouthessex.ics.nhs.uk>

World Encephalitis Day February 22nd 2024 is designed to raise awareness of encephalitis, an inflammation of the brain.

Our 10th annual World Encephalitis Day last year was perhaps our most complex to date - involving a media campaign which reached 111 million people and covered several countries, including India, the Philippines, Australia, North America, the UK, Germany and Australia.

It began with the publication of two new pieces of ground-breaking research investigating the mental health impact of encephalitis and included our spokespeople and members of our community who spoke about their experiences.

By talking about this to the media, our aim was to shine a light on the fact that these mental health issues can be preventable and, in most cases, highly treatable.

<https://www.rarediseaseday.org/news>

Rare Disease Day February 29th 2024

ITN Business and Genetic Alliance UK are co-producing 'Rare Conditions: The Stories Behind the Stats', a news-style programme raising awareness of people affected by rare, genetic, and undiagnosed conditions. Rare Disease Day is an observance held on the last day of February to raise awareness for rare diseases and improve access to treatment and medical representation for individuals with rare diseases and their families.

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



We know the more conversations we have, the better life is for everyone. Talking about mental health isn't always easy, but a conversation has the power to change lives. **Time To Talk Day -**

Time To Talk Day

**“The smallest act of kindness is worth the grandest intention”
Oscar Wilde**

Neurological conditions result from damage to the brain, spinal column, or peripheral nerves. Some conditions are life threatening, with many severely affecting people's quality of life.

There are over different 600 types of neurological conditions:

- **sudden onset conditions**, such as acquired brain or spinal cord injuries;
- **intermittent and unpredictable conditions**, such as epilepsy, ME, certain types of headaches, or the early stages of multiple sclerosis (MS);
- **progressive conditions**, such as motor neurone disease, Parkinson's disease, later stages of MS or some rare nerve conditions;
- **stable conditions**, such as post-polio syndrome, or cerebral palsy in adults.

People living with neurological disorders usually have complex health needs.

NHS Cornwall & the Isles of Scilly ICS

True stories

I walked into the cancer unit, dreading what I would hear, and found that every single member of staff greeted me with a smile and a pleasant comment, making me feel at ease before my consultation with my specialist. When one of them saw my date of birth on my notes she said, 'you don't look that old!' I felt like a new woman! I was asked what name I preferred to be called, my opinions were sought, I was listened to and treated as a person rather than just another patient. I survived the diagnosis!



A cancer patient

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 about your service or charity, or from people with neurological conditions, their families and carers, are welcome for inclusion in one of these Connexions bulletins. We shall do our best to include them at the earliest opportunity although no guarantee can be given for which edition and will be subject to availability of space. This bulletin is produced on alternate months.