

Connexions

November 2023

Bulletin No.1

Essex
Neurology
Network

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, family and friends.

Essex Neurology Network was originally founded in about 2008 and amongst other things produced the '555 Report' and the 'Understanding Neurology' online training module. This year, the Network has been relaunched, under the banner of the University of Essex. The Network is an umbrella organisation that brings together local Essex neurology service providers, national & local support organisations, and researchers, as well as people, families and carers affected by neurological conditions.

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

The aims of the Essex Neurology Network are:

- a) To raise awareness and promote understanding of neurological conditions;
- b) To secure the highest standards of service and care for people with, or affected by a neurological condition, and for their families and carers;
- c) To build strong relationships between patients and professionals.
- d) To facilitate & encourage research into the provision of services and neurological conditions.

Anyone interested can join ENN, whether you are a patient or family member, a carer or support organisation or are part of any NHS service which supports people with neurological conditions.

Membership is free – **register your interest NOW** with our secretary: essexneuronetwork@gmail.com

The Neurological Alliance

The Neurological Alliance is England's leading coalition of organisations and professional bodies supporting people with neurological

conditions – over 90 organisations working together to ensure that every person affected by a neurological condition can access the right treatment, care and support at the right time. Essex Neurology Network is planning to become affiliated to the Neurological Alliance.

At least 1 in 6 of us across the UK live with a neurological condition, which can affect anyone at any time, no matter your age, circumstance, or gender. There are more than 600 different types of neurological conditions, ranging from the very rare (affecting less than 1 in 2000 people), to more prevalent conditions you may be more familiar with, such as dementia, motor neurone disease (MND) or autism. They can impact all aspects of your life; how you think, feel, move, work and play.

[Together-for-the-1-in-6-UK-Findings-from-My-Neuro-Survey-v6.pdf \(neural.org.uk\)](#)

For the first time ever, the Neurological Alliance have worked across the UK to provide unparalleled insights into the experiences of people with neurological conditions accessing treatment, care and support. More than 8,500 people took the time to respond to their 'My Neuro Survey' and more than 35 clinics took part across the UK. Over 100 of their membership voluntary sector organisations, professional groups and regional groups worked tirelessly to promote the survey. The Association of British Neurologists (ABN), Royal College of Psychiatry, Faculty of Neuro-Psychiatry, Association of Chartered Physiotherapists in Neuroscience (ACPIN) and the British Paediatric Neurology Association (BPNA) all endorsed and promoted the survey.

Together for the 1 in 6:
UK Findings from My Neuro Survey

Shaping My Future: A planning guide for people with disabilities in Essex

This new booklet, funded by Essex County Council, and endorsed as good practice by members of ENN, can help practitioners and support workers to help people, their families and carers to make their own decisions and shape their own future. Created by 'Together Matters', the booklet can be viewed at [Shaping My Future: a new guide for disabled people to plan for the life they want | Together Matters](#) and can be downloaded from [Shaping My Future: Complete Guide pdf | Together Matters](#). A limited number of hard copies are available from: shapingmyfuture@essex.gov.uk



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](#)
- A variety of weekly online [activities](#) - exercise, chair yoga, Qi Gong and 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

Feel free to contact us on 0800 783 0518 if you'd like to find out any more about any of our services.

"The problem is that if you break your leg or your arm other people can see it. But when something goes on in your brain and you look fairly 'normal', people think you're making it up. Being unbelievably is devastating, just adding to our stress and making our symptoms worse." - Adult affected by a neurological condition

TIME FOR CHANGE SUMMIT 2023



At their recent UKABIF conference in Manchester, over 200 delegates enjoyed a fabulous day of learning, networking and collaboration. The event, chaired by our own ENN chairman Professor Andrew Bateman, was a huge success with delegates attending from across the country to hear from experts in the field of brain injury. Topics included 'Women and Brain Injury' with discussions on women in sport & domestic violence, a look at the Government's Suicide Prevention Strategy, a session on suicide and self-harm in prisons and the importance of screening for Traumatic Brain Injury. The summit was preceded by a wonderful fundraising dinner, where the winners of the annual UKABIF Awards were announced. *"What an incredible Summit that was! Thank you so much to our wonderful line-up of expert speakers for their knowledge, experience and inspiration. Wonderful to see so many people attending and hearing the conversations and seeing connections made throughout the day"*. Chloe Hayward CEO. [UKABIF Summit 2023 Draws Huge Audience - United Kingdom Acquired Brain Injury Forum](#)

True stories

A nurse went beyond her call of duty, when she stayed on the ward after her 12-hour shift ended, so she could help me have a much longed-for shower. I shall never forget her kindness!



A recently disabled hospital 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

WE NEED YOUR HELP!

If you would like to **help plan the future of ENN**, we are seeking just a few interested people to join our small friendly committee, which will meet just occasionally on-line to manage the affairs of the Essex Neurology Network. We need another patient, someone from a charity or support organisation, two people from Health or Social Care and a researcher. If you are interested or would like to know more then please email: essexneuronetwork@gmail.com



Next Essex Neurology Network Meeting
Thursday January 18th 2024 at 4pm
Title: **'Carers and Personal Assistant Retention'**

Join us for a talk by Barbara Carr from Essex Care4Carers Club, at the University of Essex or join on-line – details available in our next Connexions bulletin.