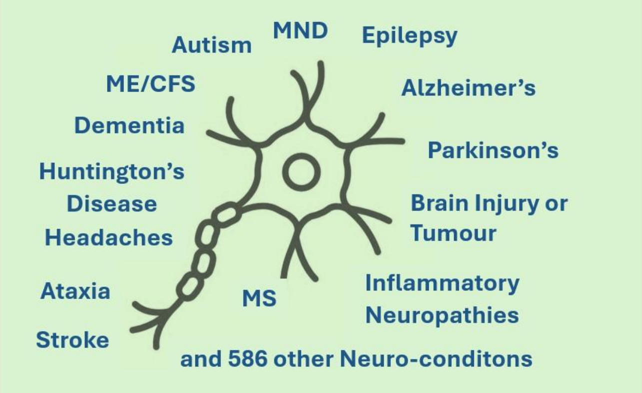
Essex
Neurology
Network

Member of the Neurological Alliance
THE NEUROLOGICAL ALLIANCE

Connexions

July 2025
Bulletin No.14

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



ENNgage with us!

In the past eighteen months we have been delighted with the huge interest in Essex in neurological conditions. Now, with over 330 people and organisations receiving our mailings, we now need to reach out to the many people in the county who actually have neurological conditions themselves.

Essex currently has a population of 1.52 million people and one in six of these people will have a neurological condition – that means that there are probably well over 250,000 people in the county in need of neurological care and support. There are, we are led to believe, more people with neuro-conditions than the total number of heart and cancer patients added together!

There are over 600 known neurological conditions, some we are familiar with and some that most of us have never heard of, which are rare or very rare. Some are genetic conditions passed on through one's genes at birth, others are acquired through accident of disease; almostall are life-changing and many are life-threatening. Each condition varies from person to person. You are likely to know someone who suffers from one of them.

Whilst some people with neuro-conditions receive invaluable support through well-established voluntary sector organisations, many, especially those with the rarer conditions, have little or no support and are frequently left to manage as best they can with their often life-long conditions.

We want to reach out to all those people in Essex with neuro-conditions. To welcome you, to listen to your stories, to offer support where we can and to learn from your 'lived experiences', so we understand what your needs are. This will help us speak up for you and to lobby for improvements in support and services.

We have already started a list of people with neuro-conditions, who are willing to share their stories with us. So … if you know someone with a neuro-condition, please encourage them to get in touch with us. We'd be delighted to hear from them and their stories will always be held in confidence and only used with their permission! Email Rosie on **essexneuronetwork@gmail.com**

Volunteers joining ENN

Last newsletter we asked for volunteers for our committee and lo and behold, like waiting for a bus, four turned up at once! We have found four great additions joining our committee, each bringing their valuavle experince and knowledge to strengthen our Voice. Thank you all for volunteering and a big welcome to all of you!

Later in the year we shall be looking for helpers to help with publicity. If you'd like to know more about how you can help then please **email Rosie** for an informal chat on **essexneuronetwork@gmail.com**

Tell us what you would like to hear about from Essex Neurology Network

Are you someone who suffers from a neuro-condition? Or do you care for someone who does? What can we do to help you? Have you a topic that you would like to know more about? Do you want to know more about research or the latest treatments? Complete this simple form and we will do our best to find someone to speak at one of our future Open Meetings. **Click here**

Become a Neuro-Activist

'Neuro-Activism' is a way of thinking about difficult questions and finding interesting ways to solve them, by using our brains & communicating that to others. Activists are normal people, like you and me. They feel passionate about what they believe in and show that by taking action and letting others know how they feel and why!

So, how can we promote understanding about neuro-conditions? And how will we go about influencing decision making? Who should we be speaking to? What do we actually want to achieve? What do we want to change?

We need to influence our MPs, the commissioners of health services and practitioners themselves to promote awareness, affect policymaking and influence decision making

Join us at the Health, Well-being and Care Hub at the University of Essex or online on **Wednesday July 2nd at 11am**, for an interesting introduction to becoming a neuro-activist. Become part of a growing movement that's pushing for raising awareness and making sure people living with neurological conditions and their families get the support they need.

You'll hear a short 20-minute presentation, where we will consider updates from the Neurological Alliance and the cost of neurological conditions to the economy. We will look at the findings published in a doctorate by Cara Knight, which has recently been published online, where we will have a very brief look at some of the Hansard discussions that she has cited and analysed. After that, we shall break into small groups for discussion, depending on number of participants.

If you are passionate about making a difference for those with neuro-conditions, then do join us
Book here to join the session

Being discharged with a spinal cord injury – Expectations v. Experience

How do the thoughts, feelings, and priorities of spinal cord injury patients before discharge from an inpatient care setting compare with the lived experience after discharge?

Volunteers who have received care for their spinal cord injury in an in-patient care setting and have been discharged in the past three years, are invited to take part in a research project being undertaken at King's College, London. David Carter, at King's College, is doing research into this for his MSc in Applied Neuroscience.

If you choose to take part in the project you will be asked to take part in an interview that will last approximately 20 minutes.It will take place either in person, via phone or video. You will be asked open-ended questions about your thoughts, feelings and priorities both before and after leaving in-patient care.The interview will not be audio-recorded, but a live transcript will be made of your responses. Your interview transcript will remain anonymous and unattributed, and you will sign or mark a consent form, which will be stored securely. The **closing date is July 1st** – if you would like more information about this research, please contact **david.g.carter@kcl.ac.uk**

Patient Partnership Week 2025: June 30th to July 4th

We are pleased to invite you, your communities, and your colleagues to this week-long programme of free online events, which will explore how genuine partnership with patients can create a fairer, more responsive, and more effective health and care system. Each event will highlight the power of patient voices, bringing together people with lived experience, NHS leaders, and professionals from across health and care. **Webinars will include:**

- **Transforming outpatient care through shared decision-making**
- **Breaking down barriers to equitable care**
- **Making digital innovation work for everyone**
- **Working together for change: a conversation with Jim Mackey**
- **Patient power: energising the 10-Year Health Plan through partnership**

Book online at: Join us for Patient Partnership Week: free webinars exploring the future of patient-centred care

The Lancet Neurology: Neurological conditions are now the leading cause of ill health and disability globally, affecting 3.4 billion people worldwide.

Encephalitis Conference - December 3rd – 4th 2025

Royal College of Physicians, London, or virtually

ENCEPHALITIS 2025 is an excellent forum for physicians, scientists, researchers, and healthcare professionals to exchange ideas, knowledge and clinical experience relating to encephalitis. Last year our conference was our biggest yet - we welcomed 514 delegates from 71 countries in-person and online. Help us make Encephalitis 2025 even bigger!

Registration is open, click HERE to book your tickets!
There are discounted tickets for students and Professional Members of Encephalitis International.

Our call for abstracts is also now open! We welcome submissions on all aetiologies of encephalitis. Please submit your abstract, by June 15th, through our online form which can be found on this page HERE. Encephalitis International | The brain inflammation non-profit

Saving the NHS money while battling malnutrition

Heather Nunn, Herts & West Essex Integrated Care Board's Lead Prescribing Support Dietitian, has helped the ICB save money in the fight against malnutrition that no other ICB in England was able to do - and won an award in the process.

By working closely with partners across the health system and beyond, Heather and her colleagues have brought tangible benefits to patients and the NHS in general. Her impressive work has caught the attention of health organisations across the country. Visit their **website** to read more about this fantastic success story.

What is Essential Tremor?

Essential Tremor is considered one of the most common neurological movement disorders and is estimated to be eight to 10 times more prevalent than Parkinson's disease. People exhibit a rhythmic trembling of the hands, head, legs, trunk and/or voice. It can afflict persons of any age, gender and race and in the vast majority of all cases it is inherited. While more commonly noticed in older individuals, essential tremor can begin as early as birth.

The Aim of the NTF is to improve the quality of life for people of all ages living with a neurological tremor.

We aim to promote research and advance the understanding of neurological tremors to better support those living with, or supporting those living with neurological tremors.

NTF Conference: 25th Oct 2025 10:30am - 4:00pm Free
Vermont Hotel, Castle Garth, Newcastle upon Tyne, NE1 1RQ
Register online at Upcoming events

Critical Care Annual Audit

In May, ICNARC held its annual meeting for the Case Mix Programme (CMP), the national audit for adult critical care. The event brought together staff from units across the UK, all working to improve care for critically ill patients.

This year's focus was on quality improvement, using data from the audit to help raise standards and improve outcomes for patients. Some of the latest research studies were also shared, showing how the audit supports better, evidence-based care. The day ended with a lively debate about the best ways to improve patient care, highlighting the passion and commitment of the critical care community.

A heartfelt thank you to the family members who also took part in our recent focus group. Your insights have been vital in shaping a new audit that looks at how satisfied families are with the care their loved ones receive in ICU. Your feedback - on everything from timing to how we send the questionnaire - has made a real difference. We're excited to keep you updated as the project moves forward!

There is a new online support group for ICU survivors and their families who have been cared for in a London hospital supported by the UK charity ICUsteps. The first meeting was held in June 2025 - you can find out more info by contacting **stella@reignitepurpose.com** **The Paediatric Intensive Care Audit Network (PICANet) are also looking for parents** & carers to join their Steering Group. For more information, please see here or contact **picanet@leeds.ac.uk**

Chelmsford **CVS**

Mayoral Charity 2025/26

We are thrilled to announce that the new Mayor of Chelmsford, Cllr Jannetta Sosin, has chosen **Chelmsford CVS** as the mayoral charity for 2025–26. Cllr Smita Rajesh is Deputy Mayor this year.

We are incredibly proud to have been chosen and can't wait to begin this special journey. Mayoral events and activities held throughout the year will raise funds to help Chelmsford CVS to continue to deliver the support we offer to local voluntary organisations.

Throughout the year, Chelmsford CVS will also look for ways to highlight the incredible work of our member organisations and encourage more people to give back to their community. Together, we aim to spark a renewed spirit of generosity, volunteering and community connection in the spirit of the Mayor's chosen theme Generosity.

Essex Neurology Network are delighted to congratulate Chelmsford CVS and thank them for all the help they have given us!

Inflammatory Neuropathies UK

The 40-year-old charity GAIN has changed its name to Inflammatory Neuropathies UK. This is a significant change for the charity, but one that we think is really important to make sure we can deliver both the objectives of the charity, as well as our long-term ambitions and goals.

So, what is an Inflammatory Neuropathy? There are around forty types of Inflammatory Neuropathies, including Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and Multifocal Motor Neuropathy (MMN). Each type has its own set of symptoms and characteristics.

These rare conditions affect the nerves in your body, causing symptoms like pain, weakness, and numbness, swallowing and breathing problems. They happen when the immune system (your body's defence against infection and disease) attacks your nerves by mistake, leading to inflammation and damage. If you know someone with an inflammatory neuropathy, then please contact us at: **hello@inflammatoryneuropathies.uk**

Shaftesbury
All together better for disability

Taking notice

This time of year, we often notice our senses coming to life; the vivid colours of flowers blooming, the sound of birds chirping, the feel of the warm sun on our skin. Over the years more and more research has revealed that noticing what we are doing when we are doing it has powerful benefits for our wellbeing. We need to take a step back and remember to take some time to be mindful and notice the world around us. By doing this, we can reconnect with ourselves and the world, creating a sense of peace and appreciation for life.

A powerful tool we have for noticing more is to simply be curious about the details of this moment, both within and around us. Take a moment to challenge yourself to be present. Choose a moment (daily or as much as feels helpful) and write down things from the list on the right. Do not worry if you can't do all of them, just do what you can.

5 things you can see
4 things you can hear
3 things you can smell
2 things you can touch
1 thing you can taste

https://www.shaftesburygroup.org

Down's Syndrome
RESEARCH FOUNDATION UK

Assisted Dying Bill

The Down's Syndrome Research Foundation is sending an open letter from a parent in the DS Community to MPs about the Assisted Dying Bill, which is likely to become law in coming weeks. They are hoping the letter will inspire others to write about their story too. To read the letter see: **An open letter to MPs about the Assisted Dying Bill from a parent in the DS Community | Down's Syndrome Research Foundation**

A guide to understanding neurodiversity

Neurodiversity is an umbrella term that refers to the natural variation in the human brain and its functions. It acknowledges that every brain is unique and that these differences are not deficits but simply alternative ways of processing information, thinking, and interacting with the world.

Each person has a brain that is unique to them; no two brains are quite the same. **Neurodiversity** is the concept that brain differences are natural variations. Some people's brains simply work in a different way. For at least 20% of the adult population in the UK, these differences mean they may be diagnosed with **neurological conditions** such as **autism**, **dyslexia** and **attention deficit hyperactivity disorder (ADHD)** and may consider themselves to be **neurodivergent**. The neurodiversity movement celebrates the full spectrum of brain differences, encompassing both **neurotypicality and neurodivergence**, and champions the strength of neurodivergent people.

Neurodivergence refers to the specific variations within neurodivergent individuals, often including people who are autistic or have ADHD or dyslexia. Understanding these differences helps to create more inclusive and supportive environments for neurodivergent individuals sin schools, workplaces, and in society.

The main seven conditions considered neurodivergent:

- **Autism** - strong abilities in pattern recognition, problem-solving & attention to detail, may struggle with social cues or sensory issues
- **Attention Deficit Hyperactivity disorder (ADHD)** affects focus, impulse control, and energy regulation. Creativity and quick-thinking abilities leads to success in innovation and fast decision-making
- **Dyslexia** - a different way of processing written language, excel in creative and problem-solving
- **Dyscalculia** - challenges with maths, but excel in non-mathematical areas & can develop strategies to navigate difficulties
- **Dysgraphia** affects the ability to write coherently and legibly, but individuals often excel in verbal communication and problem-solving
- **Dispraxia** affects motor coordination, makes physical tasks more challenging, but individuals often exhibit strong problem-solving skills and a creative approach to managing their difficulties
- **Tourette Syndrome (TS)** - involves involuntary movements and vocal tics. Individuals with TS often demonstrate strong abilities in specific areas and develop effective coping strategies to manage their symptoms.

The Brain Charity: Neurodivergent: A guide to understanding differences
Enquire today about our neurodiversity training and discover how we can help your organisation build a more inclusive environment.

Autistic adults in West Essex

Autistic adults in West Essex are invited to share experiences of post-diagnosis support. They are being asked to share their views on the support they received after being diagnosed with their condition. Healthwatch Hertfordshire has launched a quick and easy survey to help them understand what information and support autistic adults were given after receiving their diagnosis. National research has found that 70 per cent of autistic people were give no support.

The survey should take around 10 minutes to complete. It can be found on the Smart Survey website. To view the survey in another format, email the research team at Healthwatch Hertfordshire or call **01707 275978**

At National Voices, we believe that health and care services are at their best when they are designed with and around the ambitions of disabled people, people living with health conditions and people affected by health inequalities. Our team brings decades of experience and expertise on how to meaningfully involve people with lived experience in decision making around health and care. **We are here to help you strengthen your organisation's approach to strategic co-production. https://www.nationalvoices.org.uk/**

Improving access to high-impact neuro-rehabilitation

In the UK, over 150,000 people have Parkinson's, 1.3 million people are stroke survivors and 150,000 live with multiple sclerosis. Patients with these conditions can benefit from rehabilitation to improve their movement, ability to carry out daily activities & improve their quality of life.

However, according to NHS England, access to rehabilitation services within the NHS is limited. Workforce and funding shortages and geographic disparities, combined with low adherence to traditional rehabilitation programmes, reduces outcomes for patients & health and care systems.

Stroll's Reality DTx® solution facilitates safe, engaging rehab at home, using augmented reality (AR) glasses. The AR glasses have see-through lenses which ensures the real world remains visible and the content blends seamlessly to the physical space, enabling clinicians to deliver high-impact immersive therapy.

With Reality DTx patients with Parkinson's, those who live with MS and stroke survivors can access fun and engaging activities which improve their gait and balance and reduce their risk of falling, alongside improvement in clinical outcomes such as walking speed and mobility assessments. Users also report increased confidence, independence and enhanced quality of life.
Improving access to high-impact neurorehabilitation - Health Innovation East

Volunteers Support The NHS For 6 Million Hours This Year – new figures collected to mark Volunteers Week show that around 70,000 people volunteer with the NHS and spend an average of a fortnight helping their local services each year. Tens of thousands of people have volunteered to help the NHS over the last year, according to new figures. om people in their late teens to those in their late eights volunteers have helped with tasks such as directing loved ones around hospitals, collecting medication or basic admin tasks.

A Question of Time

For people living with Parkinson's, time is everything. What's possible today may not be tomorrow.

The condition is relentless, taking time and independence bit by bit. But while Parkinson's takes, research is working to give time back. With every breakthrough, we get closer to a world where no one has to fear losing their future. This is the reality for millions of people around the world, including those featured in our short film, 'A Question of Time'. This film shares their experiences – what Parkinson's has taken from them, what they hold onto, and why finding a cure is so urgent.
To watch the film: **A Question of Time - Cure Parkinson's**

Draft Model ICB blueprint

Working with ICB leaders, NHS England has co-produced a draft Model ICB blueprint clarifying the role and purpose of ICBs. It recognises the need to build strong strategic commissioning skills to improve population health and reduce inequalities while focussing on delivery of the government's 3 strategic shifts. The blueprint will support ICBs to create locally driven plans to achieve the model approach by the end of May 2025 and follows the **letter from NHS England's chief executive**, Sir Jim Mackey last month outlining how the NHS will work together to deliver our core priorities. **NHS England » Update on the draft Model ICB Blueprint and progress on the future NHS Operating Model**

Podcast | The new ICB blueprint: what's the future of system working?

NHS Confederation's chief executive, Matthew Taylor, is joined by David Melbourne, chief executive of Birmingham and Solihull ICB, and Jan Thomas, chief executive of Cambridgeshire and Peterborough ICB, **to consider how ICBs may operate in future** and how they might evolve as strategic commissioners, as well as what future relationships with local government could look like.

Today's updated NHS figures reveal a record 224,382 people in England are now waiting for an autism assessment. That's the equivalent of the entire population of Portsmouth left without answers, support, or a clear path forward.Too many autistic people are being missed, misdiagnosed, or left on waiting lists for years.

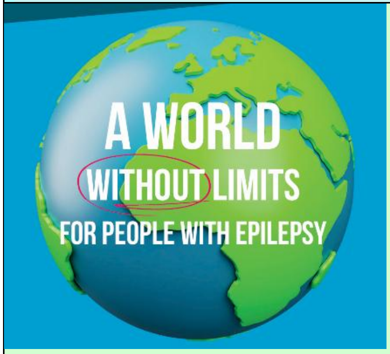
The University of Essex Cross-departmental 'Brown Bag' meetings

3rd Wednesday of each month between 4 & 5pm

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. Suggestions for session topics and agenda items are welcome. We collaborate on a Padlet to share information, contacts and opportunities: **https://padlet.com/katiechadd8/uoe-neurorehab-research-brown-bags-b8sww61e47aa22a8**

If you are interested in finding out more please email Katie Chadd katie.chadd@essex.ac.uk



Epilepsy Action has been fighting to improve the lives of people with epilepsy for over 70 years, and we've delivered some life-changing support in that time. But the recent feedback gathered from over 5,000 people impacted by epilepsy, and the evidence we have gathered across the years, demonstrates that we are not making the progress that is needed to improve the lives of everyone affected by epilepsy.

We know around 1 in 100 people live with epilepsy – that's four times more than live with Parkinson's and half the number of stroke survivors in the UK. We know there is a chronic underinvestment in research and we are hopeful that the establishment of an Institute will help change that.

We know that the unpredictability and social stigma around epilepsy can mean it is hidden. You rarely hear someone high profile talk about it in the same way as motor neurone disease or cancer. We aim for all people with epilepsy in the UK to say their lives have improved through the things we achieve together; for everyone to know what epilepsy is, and how to support people living with epilepsy and to be fully inclusive in who we are, and also who we support.
We will make a difference by being: Ambitious, Empowering, Inclusive and Supportive.
Home - Epilepsy Action

Insights' tool

A flagship 'Insights' tool to help the NHS to listen more deeply is being developed in Derbyshire. The tool being piloted in Derby and Derbyshire is helping the NHS and partners listen more deeply to local communities, ensuring their voices and experiences are heard. The Community Insights Framework is a series of practical actions to help people consider how they engage and involve the public, aiming to improve services by supporting them to talk to people and communities more effectively to understand their needs. **Flagship 'Insights' tool to help NHS listen more deeply developed in Derbyshire » Joined Up Care Derbyshire**

Laura's Story Hospice Heart Award

'Volunteering can be emotional, but volunteering makes me appreciate life and it has helped me with my grief journey by turning such a difficult situation into something positive.'
Laura received our Hospice Heart Award in recognition of her volunteering service on our ward. She gives her time to help people receive the care and support they deserve.
Read Laura's story here: **Saint Francis Hospice - Laura Cornish - Hospice Heart Award**

If you have a story about how someone or a department went out of their way to do something to make you, or someone with a neurological condition, smile, then please send it to:
essexneuronetwork@gmail.com

"Promise me you'll always remember:
You're braver than you believe, and stronger than you seem, and smarter than you think"
A. A. Milne

Short articles or adverts about neurological conditions, services or support organisations are welcome. The next edition of this news bulletin is due in September and the deadline is August 1st. Please send to essexneuronetwork@gmail.com

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