

# Connexions

October 2024  
Bulletin No.7

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*

## Open Meeting & AGM

Thursday November 7th at 4pm

Our chairman will report on our achievements in the past year and our exciting plans for the year ahead.

We met recently with the Neurological Alliance

to plan a high profile roadshow event for late Spring 2025.

Anyone interested in helping to support the planning and delivery of this event are warmly invited to contact us.

**Come to our AGM - find out our plans for next year and how you might be able to help!**

## Talk by Headway

The charity which provides support and information, as well as campaigning, for people affected by brain injury

Join us on Zoom or Face-to-Face at the Health, Wellbeing & Care Hub at the University.  
**Everyone Welcome!**

**Please book your place by completing this link:  
ENN Meeting 7th November at 4pm ([google.com](#))**

## Have you completed your #MyNeuroSurvey? Have you told others about it yet?

The national survey about people with neuro-conditions and their families & carers.

The **survey aims to understand the experiences of people affected by neurological conditions** in the UK and Republic of Ireland, and to **provide insights to inform future advocacy, influencing, and service improvement** at national and local levels.

To date the Alliance have had **6,500 responses!** Hopefully, we can inspire more people to respond so that the target of at least 8,000 is reached. The report will highlight both good & bad experiences from the whole UK, and, as a member of the Neurological Alliance, ENN will receive vital information specifically about Essex.

So, **please encourage everyone with a neurological condition or their family or carer** to share their experiences and celebrate excellent care or highlight areas for improvement. **You need to tell everyone you know about it. The days are ticking! Closing date November 15<sup>th</sup> Don't miss out!**

Details about the survey can be found via this **QR code:**  
or the following link:

[https://revealingreality.welcomes\\_your\\_feedback.net/a84.vvg](https://revealingreality.welcomes_your_feedback.net/a84.vvg)



**A poster is also attached for you to print off and display at your venue.**



**Surviving a stroke is the start of a long and difficult journey**  
**Every day** in the UK, another **240 people** wake up to the **catastrophic** impact of a stroke. It's a traumatic, **life-changing** event that robs survivors and their families of the life they knew. It can leave people unable to move, see, speak or even swallow. Survivors can also be left with personality changes and depression. But with strength, determination and the right support, recovery is possible.  
 The **Stroke Association** is **here** with stroke support for every survivor and their loved ones, for however long it takes. [Stroke Association | Strength through support](#)

**New surgical hub will cut waiting times**

A new surgical centre, that will provide patients across Hertfordshire and West Essex with quicker access to non-complex operations and procedures, is on course to open its doors from spring 2025 as construction work progresses.

The new facility, located at St Albans City Hospital, will be known as Hertfordshire and West Essex Surgical Centre, St Albans – a name that healthcare staff and patients helped choose. The local NHS which is developing the new centre decided on the name to make it clear that patients across Hertfordshire and west Essex will be given the choice of going there for treatment. It also shows that the new centre is a collaborative venture between the Hertfordshire and West Essex Integrated Care Board (ICB) and three main hospital trusts in Hertfordshire and west Essex who will refer patients into the centre and whose surgical teams will carry out operations there.

The new surgical centre will treat patients who are waiting for hip and knee surgery, spinal injections and minor ear, nose, and throat operations. It will help around 4,000 patients a year, mostly as day patients. Work is also continuing to recruit staff for the new surgical centre, with new roles being advertised this month by West Hertfordshire Teaching Hospitals NHS Trust (WHTH).



**Medics 4 Rare Diseases**

With over 7,000 rare diseases, it's understandable that not all can be known in detail. However, it's crucial for healthcare professionals to recognize that rare diseases are collectively common and to understand the unique challenges faced by patients living with these

conditions. 1 in 17 people will be affected by a rare disease at some point in their lives.

M4RD (Medical education for Rare Diseases) provides essential education on the relevance of rare diseases to everyday clinical practice, empowering doctors to better manage their patients. Our ultimate goal is to shorten the time to diagnosis and enhance the overall patient experience.

See: [M4RD Home - M4RD](#)

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**Rareminds**



Rareminds Wellbeing Hub is here to support you through the emotional challenges often experienced by those living with rare conditions. A diagnosis can affect your sense of identity, relationships, and how you navigate life with your condition. The future may feel uncertain, and at times, life can seem stressful or isolating. These feelings are normal and understandable.

Whether you've been living with your condition for a while or are currently facing a difficult period, we hope you find valuable resources and support in our Wellbeing Hub.

See: [Wellbeing Hub - Rareminds](#)



The Patients' Association would like to better understand the causes and consequences of a lack of patient preparedness on their health journey, as well as the benefits of being prepared. They are looking for patients to join a focus group, the findings from which will enable them to create accessible resources that can support patients to be better prepared, these will then be promoted to key stakeholders to ensure as many patients as possible understand and are equipped to be better prepared. If you would like to be part of a focus group on Wednesday 6th November to share your experiences of patient preparedness, then check out:

[Experiences of patient preparedness | The Patients Association \(patients-association.org.uk\)](#)

## World Patient Safety Day Letter

In August, over 2,600 patients and carers affected by ME and Long Covid wrote to Wes Streeting (Secretary of State for Health & Social Care), sharing recommendations from the **#ThereForME** campaign. They received a disappointing response and to date the Department had thus far declined to meet with the campaigners. Now healthcare workers have joined the call to action. On September 17<sup>th</sup> **#ThereForME** sent an open letter to Wes Streeting from over 200 healthcare workers to express their concerns about the safety of patients with Myalgic Encephalomyelitis (ME) within the NHS.

Today's open letter is a collaboration between **#ThereForME** and Dr. Binita Kane, who recently spoke about gaps in care for ME on the BBC Breakfast sofa. Doing nothing is not safe!

Dystonia  
UK



## Dystonia Matters Live 2025

Friday 27th & Saturday 28th June  
Radisson RED, Heathrow

### Research: The Index of ME Symptoms (TIMES) for ME/CFS

The ME Association is funding a study led by Professor Sarah Tyson (who also has ME) from the University of Manchester, to develop a clinical assessment toolkit in collaboration with people with ME and clinicians in NHS ME/CFS specialist services.

Professor Sarah Tyson says: "Many thanks to the thousands of you who have supported the clinical assessment toolkit project. We are now entering the final stages of the data collection, which is a busy time!"

The final stage of the research is to develop an assessment of ME/CFS symptoms, called The Index of ME Symptoms (TIMES) by working with people with ME/CFS and clinicians in specialist services.

[Research: The Index of ME Symptoms \(TIMES\) for ME/CFS - The ME Association](#)

### Darzi Report on the Performance of the NHS

Professor Lord Ara Darzi released his report on the performance of the NHS. The report was commissioned by Wes Streeting, the Secretary of State for Health and Social Care. The purpose of the report was to provide a 'diagnosis' of the NHS, with a focus on assessing patient access to healthcare, the quality of healthcare being provided and the overall performance of the health system.

Patients' Association Chief Executive, Rachel Power commented: "Lord Darzi's conclusion that the NHS is in a critical condition is deeply concerning but, sadly, not surprising given the experiences of many patients across the country. This diagnosis report provides a stark and necessary assessment of the challenges facing our NHS. We welcome this honest appraisal and the development of a long-term plan to address these critical issues. We now must stop normalising the abnormal."

The Patients Association said they 'welcome the honesty and transparency of Lord Darzi's diagnosis report on the state of the NHS. His conclusion that the service is in a critical condition is a stark wake-up call that demands urgent and comprehensive action. Patients deserve far better than they're getting right now.'

on



In late September, **Helen Rhodes from Fifth Sense** gave us a most interesting talk about the issues faced by people who, for a range of reasons, have lost their sense of taste or smell, raising issues that need to be considered when treating people with a range of neurological conditions. Do read more [Home - Fifth Sense](#)

## Think outside the box! Could you offer an opportunity that might change a young person's life?

Chelmsford College is seeking to secure work experience for a significant number of students. The college are keen to discover placements or volunteering opportunities, whereby students could volunteer their time to carry out work that adds value to the local and regional environment. This could include any number of different activities from tree planting projects, litter picking, repainting, or even **helping to support local events**, etc. The week when students have the opportunity to carry out work experience/voluntary work falls between 24/02/25-28/02/25. If your organisation is able to provide opportunities, please get in contact with us to discuss. [volunteercentre@chelmsfordcvs.org.uk](mailto:volunteercentre@chelmsfordcvs.org.uk)

**ALICE OSEMAN  
ARTWORK RAFFLE  
1ST - 31ST OCTOBER**

**EPILEPSY  
ACTION**



**TICKETS £10  
PER ENTRY**

**Original A5 Artwork of Heartstopper's Nick Nelson  
& Charlie Spring, hand-drawn by Alice Oseman!**

[epilepsy.org.uk/raffle](http://epilepsy.org.uk/raffle)

Alice Oseman is best known for being the author & illustrator of the best-selling Heartstopper series, and a screenwriter on its Netflix counterpart.

Last weekend, as part of National Doodle Day, one of Alice's artworks raised over £1,700 in aid of Epilepsy Action. Whilst this amount is absolutely incredible, we know that many of Alice's fans, as well as many people living with epilepsy, aren't able to afford this sum.

So, this is your opportunity to win an original A5 illustration of Heartstopper's main characters, Nick Nelson & Charlie Spring, hand-drawn by Alice herself! We believe that everybody deserves an opportunity to own this one-of-a-kind artwork, so we've decided to hold a raffle for it!

Tickets are available for £10 each, and they will be on sale from now until 31st October, when one lucky ticket holder will be selected at random.

[Calling all Heartstopper fans! - essexneuronetwork@gmail.com - Gmail \(google.com\)](mailto:essexneuronetwork@gmail.com)

**Epilepsy Action are thrilled to announce that, thanks to the incredible generosity and creativity of our supporters, we raised an astounding £23,686.18 as part of our National Doodle Day!**

## Coroner demands urgent action to prevent further deaths from ME

The health secretary and NHS officials must urgently address the "non-existent" care available to ME sufferers and the lack of funding for research into the condition or risk more deaths like that of Maeve Boothby O'Neill, a coroner has urged.

Deborah Archer, who conducted Maeve Boothby O'Neill's inquest, issued a Prevention of Future Deaths Report, the first of its kind involving the poorly understood condition of myalgic encephalomyelitis. The coroner concluded that Maeve Boothby O'Neill, 27, died of malnutrition as a result of ME and has called on Wes Streeting, NHS officials and other health bodies to take urgent action.

The Prevention of Future Deaths Report outlines how, despite Maeve being tube-fed during one admission, it was not sufficient for her to recover. Care for patients with severe ME "is nonexistent" and hospital admissions were "very difficult for Maeve to endure" because of the lack of expertise on wards.

The report highlights the absence of specialist beds across the country for severe ME patients, which meant there was no treatment. It also called attention to the fact there was no funding available for research into ME, and that training for doctors was "extremely limited". It also about raised shortcomings in NICE guidelines on ME, in particular about how nutrition support should be handled for severe patients.

**Essex Neurology Network** took part in the very successful 'Can Do' Health & Care EXPO2024 at Colchester in September. Run by Suffolk and North East Essex ICS, 1,200 delegates were brought together at Colchester Rugby Club, to celebrate and share all the amazing work going on in the SNEE area to improve the health & well-being of local people. Along with the other 159 exhibitors, ENN were able to share information with a wide audience of other professionals and charity organisations and to welcome new members to the Network. It was agreed it had been a very worthwhile event!



We all know how worrying it can be when your child is unwell. In coming weeks, subscribers to Mid & South Essex Children's Health Matters topic will receive weekly emails from local health and care professionals.

Each email is packed with tips and advice to help you care for your child's health and wellbeing, as well as information to help you better understand common childhood illnesses.

From time to time, you will also be sent additional updates with helpful information that can support the health of your family. We encourage you to explore the *Children's Health Matters* hub, where you'll find more resources. Subscribe to newsletters & choose Children's Health option:

[Newsletters - Mid and South Essex Integrated Care System \(ics.nhs.uk\)](https://ics.nhs.uk)



**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/uo-neurorehab-research-brown-bags-b8sww61e47aa22a8>

Please register here on the online [online form](#) or email Katie Chadd: [katie.chadd@essex.ac.uk](mailto:katie.chadd@essex.ac.uk)

**Health, Wellbeing and Care Hub**



**Working age  
exercise group**

If you are living with a long-term condition, would like to stay active and meet others, please contact us for more details and to sign up to our weekly session.



**Join us and have fun**

Starts Thursday 24<sup>th</sup> October 2024 4pm – 5pm

T 01206 872460

E [healthwellbeingcare@essex.ac.uk](mailto:healthwellbeingcare@essex.ac.uk)

Health, Wellbeing and Care Hub, Clingoe House, Knowledge Gateway,  
University of Essex, Boundary Road, Colchester, CO4 3GS



In their survey of neuro-patients in March/April this year, more than half of those who shared their experiences were waiting for NHS care. In England, at the same time the questionnaire was live, more than 230,000 people were waiting for an NHS neurology appointment, and more than 55,000 people were

waiting for NHS neurosurgery.

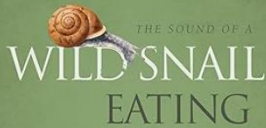
44% of respondents who were waiting for care said they had not received any information from the NHS whilst waiting. People with multiple neurological conditions were most likely to report this. 34% of all respondents described communication from the NHS whilst waiting for care as poor. 53% said they felt anxious, 35% said they felt hopeless – an increase from January/February. Just 14% felt well supported. In parallel, 43% of people said their mental health needs were not being met at all.

Read the March – April 2024 Full Insights Report **The impact of long waits for NHS care on people affected by neurological conditions.** [NeuroLifeNow](#)



“Having the support of the charity was a lifeline for me. It made me feel less alone and less scared. I have had the opportunity to mix with other people in the Huntington's disease community, and I have been able to attend webinars that are educational about things that are overwhelming, like testing and life insurance. As a whole I feel much happier being in contact with the charity.”

Read the HDA latest Annual Report on their website: [Thank you from the Huntington's Disease Association - essexneuronetwork@gmail.com - Gmail \(google.com\)](#)



ELISABETH TOVA BAILEY

**The Sound of a Wild Snail Eating** is the delightful account of how a close connection with nature brought joy to a woman incapacitated through illness.

While an illness keeps her bedridden, Elisabeth Bailey watches a wild snail that has taken up residence in a terrarium alongside her bed. She enters the rhythm of life of this mysterious creature, and comes to a greater understanding of her own confined place in the world. In a work that beautifully demonstrates the rewards of closely observing nature, she shares the inspiring and intimate story of her close encounter with *Neohelix albolabris* – a common woodland snail.

Intrigued by the snail's world – from its strange anatomy to its mysterious courtship activities – she becomes a fascinated and amused observer of the snail's curious life. *The Sound of a Wild Snail Eating* is an affirmation of the healing power of nature, revealing how much of the world we miss in our busy daily lives, and how truly magical it is.

A remarkable journey of survival and resilience, *The Sound of a Wild Snail Eating* shows how a small part of the natural world can illuminate our own human existence and deepen our appreciation of what it means to be fully alive.

**Recommended by a friend with MS**

**Available from Amazon £9.39**

## Neuro Rehabilitation Team at Colchester Hospital

Functional neurological disorder (FND), previously regarded as a diagnosis of exclusion, is now a rule-in diagnosis with available treatments. This represents a major step toward destigmatizing the disorder, which was often doubted and deemed untreatable. FND is prevalent, generally affecting young and middle aged adults, but can cause severe disability in some individuals. An early diagnosis, with subsequent access to evidence based rehabilitative and/or psychological treatments, can promote recovery, albeit not all patients respond to currently available treatments.

A new Education Group for FND (Functional Neurological Disorders) for patients diagnosed with a Functional Movement Disorder, is being set up for patients in the Colchester area. Patients will need to have been diagnosed with FND, accepted the diagnosis and have a limb weakness. Patients will initially be triaged by telephone and if accepted would have up to four physiotherapy sessions and four neuro-psychology sessions. The new project is welcomed; although there are good National Education Groups, to have one in Colchester is exciting. Doctors have, in the past, been very dismissive of these patients but running this course will enable the Team to gather evidence, discover what has worked and find measurable outcomes. It is hoped eventually to be able to offer this to other conditions such as functional seizures and to people with functional speech difficulties. Dr Rhiannon Quann, Principal Clinical Psychologist, said that she is keen to keep mental and physical health together, to view the patient as a whole person. Using this compassion as a role model will then come through to patients and create better outcomes.

## True stories

In the film *Patch Adams*, Robin Williams had a famous line: "You treat a disease, you win, you lose. You treat a person, I guarantee you, you'll win, no matter what the outcome." Nurses constantly go out of their way to live according to this inspiring mantra.



When Mary was first diagnosed with colon cancer, she was shattered and wondered how life could continue. Helen, her Irish nurse, turned out to be her guardian angel. "You're stronger than you think you are," she said. She had had colon cancer herself. She was able to listen to Mary's concerns, to reassure and comfort her, sharing tears with her and holding her hand through the worst days. Mary survived despite her early fears and went on to help others like herself.

*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](mailto:essexneuronetwork@gmail.com)*

**Short articles or adverts about neurological conditions, services or support organisations are welcome. The next deadline is November 1st. Please send to [essexneuronetwork@gmail.com](mailto:essexneuronetwork@gmail.com)**

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