

# Connexions

May 2024  
Bulletin No.4

Essex  
Neurology  
Network



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

*This news bulletin brings together news and information about Essex and national 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*



The Essex Neurology Network is very soon hoping to become affiliated to The Neurological Alliance, 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.

## It's time to #BackThe1in6 neuro survey

1 in 6 people in the UK live with a neurological condition, but there simply aren't the workforce or services in place to support them. This must change. Over 19,000 people from across the UK signed the Neurological Alliance's petition calling on all UK governments to work together to establish a UK-wide Neuro Taskforce and deliver real change. This call to action is backed by the findings from the 2021/2022 UK-wide survey of adults and children affected by neurological conditions, My Neuro Survey. Over 8,500 people took part and shared their experiences. Watch this page for further exciting news!

See: [#BackThe1in6 – My Neuro Survey – The Neurological Alliance \(neural.org.uk\)](#)



St. Luke's Hospice (Basildon and Thurrock) 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. Anyone living in Basildon and Thurrock can call on us 24 hours a day, seven days a week. Working alongside other healthcare providers, our specialist services are available at the Hospice, out in the community or in a person's own home. Together, we fulfil people's choices at the end of their life. We are a charity and the services we provide are free. We rely on voluntary income from local people to deliver the care they deserve. Every day is a varied day and the care we can provide for people is one of a kind.



Kelly Watts is the Lead Clinical Skills Facilitator at St. Luke's Hospice, where she has worked since 2017. She has always had a keen interest in education, providing support to all the staff, whilst sharing clinical skills and clinical practice. She is also the lead for student healthcare staff at the hospice. Kelly will be telling us more about the work of the hospice and the support they provide, at our next open meeting.

**Next Open Meeting on Thursday May 23<sup>rd</sup> at 4pm**

**Kelly Watts** talking about their **Neurological Study Day at St Luke's Hospice**

Join us at the University or by Zoom – please email [essexneuronetwork@gmail.com](mailto:essexneuronetwork@gmail.com) if you would like to book a place or to be sent the zoom link. **Everybody welcome!**



GAIN (Guillain-Barré and Associated Inflammatory Neuropathies) is the only UK charity dedicated to supporting people impacted by Guillain-Barré Syndrome and other related inflammatory neuropathies. GAIN is a well-respected national charity reaching and supporting thousands of people impacted by GBS, CIDP, MMN and other life-changing conditions each year.

GBS is an autoimmune neurological condition that affects the nerves that control movement and senses (the peripheral nervous system). It can cause numbness and weakness, and some people may be completely paralysed or may require intensive care treatment. GBS impacts people in very different ways and everyone's journey is different.

CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) is a rare progressive condition that is characterised by gradually increasing sensory loss and weakness over a longer period of time. Long term treatment and support may be needed.

Around 1,300 people are impacted by GBS, CIDP, and related conditions each year, and for many people the impact on them and their families is significant.

GAIN provides support, information, and advice to people impacted by GBS and other related conditions. The charity also carries out and funds research, as well as raising awareness around these rare yet life changing conditions. GAIN does not receive any government funding, instead we rely on donations and funding from the public to provide services, and to seek access to new treatments and tools to support people's journeys through GBS, CIDP, and related conditions.

To find out more about GAIN then check out our social media channels (@gaincharity) or visit our website

[www.gaincharity.org.uk](http://www.gaincharity.org.uk).

To contact us please email [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk) or call 01529 469910.

## May is GBS & CIDP Awareness Month

May is GBS and CIDP Awareness Month, and we hope that you will join us in celebrating the GBS/CIDP community and help us to spread the word about the impact of GBS and CIDP, as well as the work GAIN does. We want to reach as many people as possible, and will be holding some online events, as well as providing information across our social media and website.

If you'd like to help out by sharing your story or being involved in a webinar then please get in touch through the office.



**Huntington's Disease Association**

Huntington's disease is an illness caused by a faulty gene in your DNA. Young people affected by Huntington's have made a video: 'You are not alone'. A brilliant video with young people talking about their disease. Inspiring and informative!

See: [You are not alone | Huntington's disease youth engagement service \(youtube.com\)](#)



**National Smile Month: May 13<sup>th</sup> to June 13<sup>th</sup>**

What is the link between gum disease and strokes? Several studies have looked at the connection between mouth infections and strokes and found a link between these.

[National Smile Month | Home | Oral Health Foundation \(dentalhealth.org\)](#)



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.

**Coming sessions:**

- **Thursday 16 May, 4-5pm** The launch of the Health and Wellbeing Hub at the University of Essex.
- **Thursday 13 June, 4-5pm** -The recent Association of Chartered Physiotherapists in Neurology Conference.

To find out more about upcoming events and to register, please visit:

<https://forms.office.com/r/7rubkZYVEZ> or email Katie Chadd on [katie.chadd@essex.ac.uk](mailto:katie.chadd@essex.ac.uk)

**Involving Service Users & Carers in Research**

Nobody understands what we need from the next generation of health and social care staff more than the people who use the services themselves. The real experts ... those with the real-life experience and expertise to help influence future generations of health and social care staff.

The School of Health & Social Care recognises the value of service user and carer involvement, also known as public and patient involvement, and are fortunate that for several years we've been supported by our Service User Reference Group (SURG). The group connects academics and students with service users and members of the public who are willing to share their lived experience to promote best practice and enhance healthcare education.



By sharing their personal stories and different perspectives our SURG members help students understand the diverse needs and expectations of a wide range of people. Their active involvement and unique insights into service delivery can encourage students to develop the right values, knowledge and attitudes when engaging and supporting the public.

There are a range of activities within the School where SURG members are actively involved, including many research opportunities that may require their expertise. Staff, working alongside SURG, can support students apply and relate theory and research into their practice. This means that engaging, sharing, and learning in the School is a joint endeavour, with service users, carers, students, academics, and practice colleagues working in partnership.

If you would like to find out more about Service User engagement and SURG in the School of Health & Social Care, please contact: Dr Mary Kennedy, Lead for Service User Engagement at [mrkenn@essex.ac.uk](mailto:mrkenn@essex.ac.uk) or [surg@essex.ac.uk](mailto:surg@essex.ac.uk)



This year, **World Blood Donor Day 2024** takes place on Friday June 14th. The theme for this year is "Give blood and keep the World beating". The event serves to raise awareness of the need for safe blood and blood products and to thank voluntary, unpaid blood donors for their life-saving gifts of blood.

Safe blood supplies are a scarce commodity – especially in developing countries. World Blood Donor Day is an occasion to raise awareness of the problem and thank donors worldwide. It is held annually on June 14th.



**According to the Lancet Neurology:** Neurological conditions are now the leading cause of ill health and disability globally, affecting 3.4 billion people worldwide. The most comprehensive research to date found the burden of neurological conditions is much greater than previously understood and affects 42% of the world's population.





### Accessing Physical Activity Opportunities

The benefits of being physically active and exercising are well known, but there are persistent inequalities in how physically active people are, with people living with long-term health conditions being particularly affected. Dr Anna Pettican is a researcher and occupational therapist within the School of Health and Social Care at the University of Essex, who has a particular interest in undertaking work to address such inequalities. Anna has recently completed a study with people with disabilities, funded by Research England's Participatory Research Fund, which explored their experiences of accessing leisure centres.

She is also engaged in ongoing work to design, implement, and evaluate interventions that provide opportunities for people living with long-term health conditions to move more and be physically active. Anna says: "I am keen to connect with individuals, community groups and local organisations who are also interested in addressing the inequalities in physical activity participation and movement that too often exist for disabled people and people living with long-term health conditions. Please do get in touch if you are interested in working together: e: [anna.pettican@essex.ac.uk](mailto:anna.pettican@essex.ac.uk)



### Norfolk and Waveney Acquired Brain Injury Network

Improving lives impacted by brain injury. We support adults impacted by brain injury, resulting from, but not necessarily limited to, stroke, road accidents, trips and falls .

### NWABIN conference – Improving Outcomes for people with ABI

19<sup>th</sup> June 9.30am – 4.30pm at Wymondham Rugby Club. Face to face event only. Places are limited and booking up fast! For further details, please contact [amanda\\_cousins@btinternet.com](mailto:amanda_cousins@btinternet.com)

12<sup>th</sup> November 1-2pm BSRM updated guidance on Specialist nursing homes, which is due for publication later this year. If you would like to be sent the Teams link for this catch-up session, please contact [amanda\\_cousins@btinternet.com](mailto:amanda_cousins@btinternet.com)

[ABIRA | Headway Norfolk and Waveney \(headway-nw.org.uk\)](http://headway-nw.org.uk)

Note that there is also Headway here in Essex  
[Headway Essex | Brain Injury Charity](#)



### Carers Week: 10-16 June 2024

National charities have joined together to launch the theme for this year's Carers Week and to raise awareness of 5.7 million unpaid carers across the UK. UK and charity supporters have shared the theme for Carers Week 2024, which is '**Putting Carers on the Map**'. The new theme for 2024 aims to galvanize activity in a general election year, to highlight the increasing pressures carers and to campaign for much-needed recognition and support.

Carers Week is a UK-wide awareness campaign seeking to increase visibility for carers with decision makers, services, employers, communities, and businesses.

[Carers Week 2024's theme has been launched | Carers Week](#)



### Carer's Compendium

For information about and for all carers , see our ENN Carer's Compendium on our webpage soon. Support groups, information, articles about and for both paid and unpaid carers and families seeking care and carers.

[Essex Neurology Network | University of Essex](#)

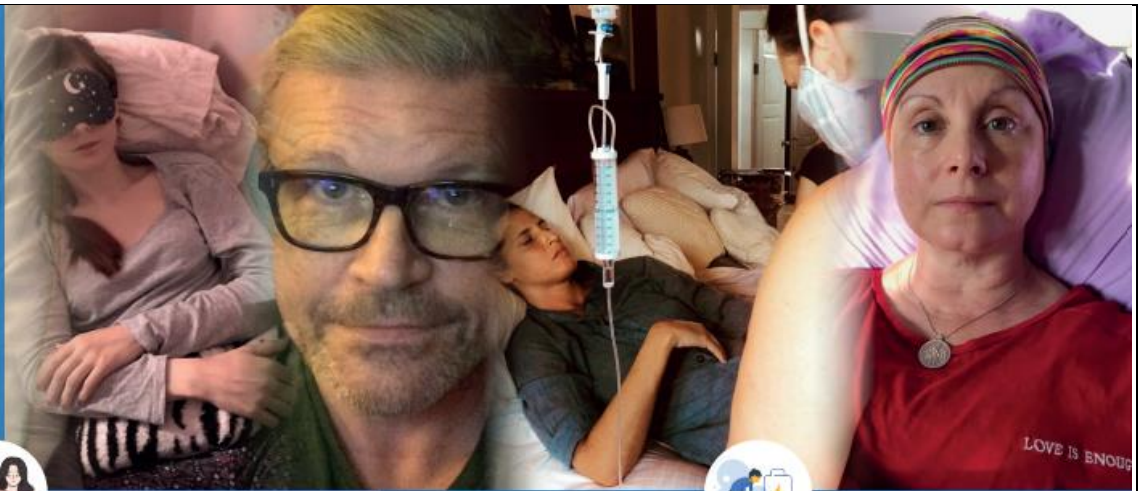


*"We want carers to know they are not forgotten, and they are not alone. The dedicated, committed support unpaid carers provide day in day out has been valued as the equivalent of a second NHS, but often carers tell us that they feel unseen and undervalued. Many are at breaking point, facing challenges managing caring alongside their own health and wellbeing – with 78% of carers worried about being unable to care in the future.*

*"Recognition for carers in their communities and at national government level during an election year, has never been more important – making Carers Week a vital opportunity to put carers on the map."*



The charity for people with ME/CFS and Long Covid



Did you know that 1.25m people in the UK are likely to be affected by ME/CFS and Long Covid?

These life-changing medical conditions have a devastating impact on a person's health and wellbeing.

Individuals are often unable to work, attend school, or complete normal everyday activities.

For some, it means that daily survival is dependent on the care and support of others.



### The ME Association

- is a lifeline for people in need of support
- provides a full-range of free and expert information
- works to improve health and social care for all
  - campaigns on issues of importance
  - invests in medical research
- is committed to finding effective treatments

We're here for you!

Changing attitudes and improving lives...

meassociation.org.uk | Helpline: 0344 576 5326 (10am-12pm, 2pm-4pm, 7pm-9pm 365 days a year)

## Decode ME

The ME/CFS Study



It is estimated that more than 1.25 million people in the UK live with a diagnosis of ME/CFS and Long Covid. It is not known how many are undiagnosed, but it represents a very real health crisis. DecodeME is a groundbreaking research initiative aimed at uncovering the genetic causes of Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS). People with ME/CFS are at the heart of the study, with patients, carers, scientists, and a steering group collaborating to advance research. It is the largest-ever study world-wide, investigating biological differences in people with ME/CFS. It aims to explore genetic factors that may be linked to the development of ME/CFS. DecodeME aims to pave the way for effective treatments and effective drugs, once the results highlight the cause. Insights gained from this study will contribute to unravelling the underlying mechanisms of the condition. The results are due in 2025.

See [Home - DecodeME](#)

### True stories:

#### An exemplary and inspiring person!

In the next bed to me on the ward was an elderly lady in her 90s, with dementia. She had nobody to visit her and was lonely and confused, always agitated and wanting attention.



One day, she needed to have a scan, which involved taking her down, on her bed, several floors to the X-Ray department. A porter arrived to take her down to the unit, but she was very frightened and flatly refused to go anywhere. Another, more senior porter was called for and he spent about an hour persuading her that she would be completely safe and he, personally, would look after her. The scan was done successfully and she returned to the ward.

For the next week, that porter came to visit her every single day. He even brought her a soft toy rabbit. Sometimes she was awake and he chatted for a while, promising to return next day. At other times she was asleep and did not realise he had visited. She got to know him and to feel safe & secure in hospital, making it better for her and easier for the other staff to care for her.

If you have a story about someone who went out of their way to do something special to help you, or someone with a neurological condition then please send it to: [essexneuronetwork@gmail.com](mailto:essexneuronetwork@gmail.com)

## HOT OFF THE PRESS NEWS:

### NHS Herts and West Essex Integrated Care Board's Patient Engagement Forum

N.B. This Forum is only relevant to those of you working or living in the NHS Herts and West Essex area. For those of you in this area, please pass on to anyone relevant that you know of, especially patients.

In an exciting initiative led by the NHS Herts and West Essex Integrated Care Board's recently established Patient Engagement Forum (PEF -created to ensure that the ICB hears the patient voice), we're launching a closed Facebook group to facilitate discussion, support, fact finding and create a two-way flow of information to ensure the patient really is at the heart of everything the local NHS does.

The PEF's commitment to you is:

- **To listen to what is important to you**
- **To follow up on anything that is critical; and**
- **To report back on the outcomes from this work.**

As a closed group, it is only open to people who live or work in Hertfordshire and west Essex, you can be sure of a safe and secure environment in which everyone respects each other and seeks to share experiences.

The 'welcome' page asks a series of questions about what is important to you; share your thoughts and see what others are saying.

Please join this new initiative and have your say – not just once, but whenever you wish to share your views.

<https://www.facebook.com/groups/hwepef>

**See following item**



**The Patients' Association** is an independent patient charity campaigning for improvements in health and social care for patients.

Uniquely for a charity with a remit covering all health and care issues, we work with patients directly: they are our members and supporters, and also the people who benefit from our help and information services. Through our helpline we provide information to thousands of people each year about the health and social care system. We also speak to government, the NHS and other stakeholders about patients' priorities and concerns, to ensure the patient voice is heard and acted upon.

#### **The six key principles of patient partnership:**

- **Treating patients as equals**
- **Patients who are fully informed**
- **Shared decision making and patient partnership**
- **Recognising inequalities**
- **Seeking patient input**
- **Joining services around patients**

We have engaged extensively with patients in developing these principles, as well as a network of national and local organisations and health and care thought leaders. Our purpose is to ensure that everybody can access and benefit from the health and care they need to live well, by ensuring that services are designed and delivered through equal partnership with patients.

w: <https://www.patients-association.org.uk> e: [helpline@patients-association.org.uk](mailto:helpline@patients-association.org.uk)

**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 ENN bulletins.

Please send to [essex.neuronetwork@gmail.com](mailto:essex.neuronetwork@gmail.com) as soon as possible