Essex Neurology Network

Member of the Neurological Alliance
THE NEUROLOGICAL ALLIANCE

Connexions

May 2025
Bulletin No.13

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

the patients association
Listening to patients, speaking up for change.

We were delighted to host **Sarah Tilsed Head of Partnerships and Involvement** at the **Patients Association** to talk to ENN at our last open meeting.

In a stimulating talk entitled **"The Power of Patient Partnership"** in healthcare, Sarah explained that the Association seeks to "Make sure everyone can access and benefit from the health and care they need to live well. They present a clear rationale that patients should be involved in the design and delivery of care. This is in the context that the Darzi Report (2024) highlighted that "lack of patient voice and staff engagement" have negatively impacted NHS performance.

Our speaker highlighted the following points:

The Six Principles of Patient Partnership

1. Treating patients as equals
2. Patients who are fully informed
3. Shared decision making and patient partnership
4. Recognising inequalities
5. Seeking patient input
6. Joining services around patients

Benefits of Patient Partnership

- Improved quality and outcomes
- Patient safety
- Cost effectiveness

There were many interesting points made but some disturbing statistics stayed with us after the presentation. Patients reported in a survey:

"I love the NHS but... they indicated 8% were not notified about something important with their treatment; 16% were not kept properly updated whilst waiting for treatment, 9% had mistakes in communication they'd received about treatment and 14% had a problem with a referral."

The meeting was well attended with a wide range of participants bringing their different perspectives to a lively discussion after the presentation. The intersectional and inequalities themes were of particular interest. There is much to do to improve things and supporting the Patient's Association by joining or providing financial support is something that I think many members of our Essex Neurology Network may wish to consider! ***Professor Andrew Bateman – Chair of Essex Neurology Network.***

Patient Partnership Week 2025
Monday 30th June - Friday 4th July

Patient Partnership Week – June 30th to July 4th showcases the power of patient partnership and all the very best in patient engagement, co-production and working with communities to improve healthcare.

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 the government, the NHS and other stakeholders about patients' priorities and concerns, to ensure the patient voice is heard and acted upon. For further information see: **The Patients Association**

Wanted! Volunteers to join our ENN committee

The ENN team are looking for people with an interest in neuro-conditions, whether you are someone with a condition yourself, a family member or carer, or someone who works in neuro-support services or a charity. If you'd like to know more then please **email Rosie** for an informal chat on **essexneuronetwork@gmail.com**

Our Next Open Meeting

SURVIVING FATIGUE

Russell Fleming

Head of Project Development
The ME Association

Thursday May 22nd at 4pm

By Zoom or in person
at the Health, Well-being & Care Hub, University of Essex

To save a place, please book here

Zoom link to follow nearer the time

Fatigue is a very common symptom of many neurological and other conditions. It is a debilitating condition that does not go away with sleep or rest and can interfeer with daily life, making it difficult to carry out everyday tasks and activities.

Come and join us and pick up some tips or hints to help you manage fatigue and other symptoms or that you can pass on to your patients.

The talk will link with sessions being run at the Universiy of Essex's Health, Well-being & Care Hub and also by Colchester's Community Neuro Team

Tell us what you would like to hear about from the 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.

Essex Neurology Network

We'd like to hear from you about what topics you'd like us to cover

Click here

Hot off the Press Today!

Well, this is very big news. GAIN is changing 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.

It may be a change of name, but it certainly isn't a change in the scope of the charity. We are still here to support everyone impacted by Inflammatory Neuropathies, to raise awareness of these life-altering conditions, to fund and undertake research into them, and to campaign for and advocate for the Inflammatory Neuropathies community. **See: https://www.inflammatoryneuropathies.uk/**

ICS Bulletin

Catch up on the latest thinking from the NHS ICS Bulletin

Sign up on: NHS England » Integrated care system bulletin

Nerve Tumours UK Virtual Coffee Mornings

We are a community driven charity and we know that a community works best when it's finding new ways to connect and evolve.

Starting on May 7th: Be a part of the conversation by attending one of a series of new Virtual Coffee Mornings facilitated by our charity director Karen Cockburn.

Connect with others, make new friends, and let us know about the issues you're facing as a member of the NF community & get your voice heard in shaping our services. Spaces may be limited, so we recommend registering your interest as soon as is convenient via the link below.

https://nervetumours.org.uk/news/nerve-tumours-uk-online-coffee-mornings

FREE Exciting New Opportunity

Colchester United Community Foundation has an exciting new opportunity to share that may benefit the individuals and families you support across Essex.

Starting Friday 25th April, we're launching a free 12-week pilot of Neuro Walking Football – a slower-paced, inclusive version of football specifically designed for adults aged 18+ living with neurological conditions such as Parkinson's, MS, stroke recovery etc.

These sessions are built around the needs of individuals managing neurological conditions. Participants can expect a welcoming, adaptive, and social environment, with benefits including:

Whether someone is newly diagnosed, returning to activity after rehab, or simply looking for a way to stay active and connected, this programme is designed to meet them where they are.

Venue: Community and Sports Centre, Boadicea Way, Shrub End, Colchester, CO2 9BG

starting Friday 25th April 2025 12pm – 1pm For more information contact: 01206 755 160

Sign up https://colchester-united-cf.classforkids.io/term/738

How can we improve the public's view of the NHS?

Public satisfaction with the NHS is at an all-time low according to the latest data, but what can be done in the short term to improve matters while NHS leaders try to make long-term change? Rachel Power of the Patients Association* and Leonora Merry of the Nuffield Trust delve into the data with Matthew Taylor and suggest what can be done. This episode's Leader in Six is with Steve Williamson, chief executive of Royal Cornwall Hospitals NHS Trust.

Click here to hear about: **How can we improve the public's view of the NHS? | NHS Confederation**

What's the way forward with NHS cuts?

Integrated care boards must cut their budgets by 50 per cent and acute providers are expected to roll back 50 per cent of corporate cost growth since 2020. This on top of NHS England winding down within two years and transitioning functions into the Department for Health and Social Care. Matthew talks to two leaders navigating these challenges: Amanda Sullivan, chief executive of Nottingham and Nottinghamshire ICB and 'Foluke Ajayi, chief executive of Airedale NHS Foundation Trust and vice-chair of the NHS Confederation.

Listen to Matthew Taylor as he talks to two leaders navigating these challenges: **Amanda Sullivan**, chief executive of Nottingham and Nottinghamshire ICB and **'Foluke Ajayi**, chief executive of Airedale NHS Foundation Trust and vice-chair of the NHS Confederation.

Click here to hear: **What's the way forward with NHS cuts? | NHS Confederation**

Hereditary Brain Aneurysm Support

Patients - we need your help to create a patient guide for the newly diagnosed.

When you were first diagnosed with a hereditary brain aneurysm, what worried you most? What information did you wish you had available? We know how overwhelming that first moment can feel.

We want to help newly diagnosed people to not feel alone— and your experience can help others who are just starting this journey. 💙

Please take our **quick 5-minute survey** to help us understand what our guide should include.
Hereditary Brain Aneurysm Support - April Update

May 12th - May 18th Mental Health Awareness Week

Mental health is important to everyone – it's estimated that around 1 in 4 people in England will experience a mental health issue at some point in their life. Mental Health Awareness Week is vital because it shines a spotlight on mental health, encouraging open conversations, reducing stigma, and promoting wellbeing. It's an opportunity for individuals, communities, and organisations to come together, share stories, and advocate for better mental health support.

The theme is set by the **Mental Health Foundation** ever year, and for 2025 the theme is **'community'.** Community is an ideal theme for Mental Health Awareness Week - social connections and community are vital for mental health and wellbeing. Through meaningful relationships and community participation, we gain support systems that help us navigate life's challenges. Communities provide emotional support, companionship, & a sense of belonging that reduces isolation. Strong community networks offer practical and emotional assistance during difficult times, helping people build resilience and find purpose through shared experiences and mutual support. **Mental Health Foundation | Everyone deserves good mental health**

Stroke Awareness Month

Every day in May, 240 people will wake up rob the life-changing impact of a stroke. We want to help people like you to get the support you need.
This #StrokeAwarenessMonth in May, help us to raise awareness of what it means to survive a stroke, so that we can help more people find strength through support. We'll be sharing the TV advert across our Stroke Association media again too – please share our social posts this Stroke Awareness Month. **Stroke Association / Finding strength through support**

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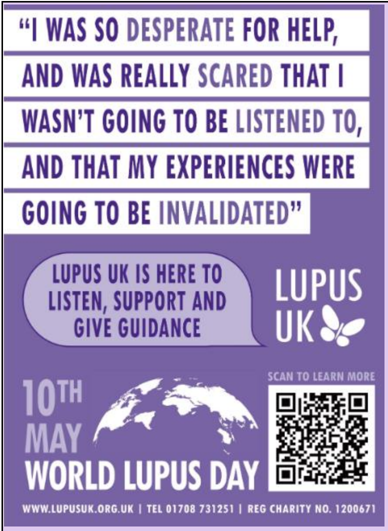
Turning Points after Stroke

Welcome to a series of webinars entitled "Turning Points After Stroke" led by Essex University in association with the Stroke Association over Zoom. This free series is open to people living with the consequences of stroke, their carers and professionals supporting them. The series has been designed with the help of the Steering Group members Jayesh, Graham; Belindah (who each are Stroke Survivors) and Andrew, Sophie and Lauren (who are based at the University of Essex).

Subjects covered will be: Turning Points in Stroke Research, Raising Awareness of Stroke; Campaigning for Change, Psychological Wellbeing after Stroke, Writing for Rehab, My Turning Point in managing Energy; Fatigue, Life after Stroke for Me.

Please **click here** or scan the QR code to find out more and register.
These webinars are every week for 6 weeks:
Wednesdays from April 30th to June 4th 2025

Muscles. We use them to move. Walk, eat, smile, cry. Pump blood around our bodies. To breathe in and out. Our muscles matter! We're the leading charity for over 60 muscle wasting and weakening conditions. Connecting more than 110,000 people affected, and those around us. https://www.musculardystrophyuk.org



World Lupus Day: May 10th

Lupus is a chronic autoimmune disease where the immune system is dysfunctional and mistakenly identifies the body's own tissues as foreign invaders. In people with lupus, the immune system creates autoantibodies to attack the body's tissues. These form immune complexes which cause inflammation and damage affecting the organs, joints or nerves. Lupus disproportionately affects females and people from Black African, Caribbean, and Asian ancestries.

Knowledge can help those who are looking for answers and provide support and hope to people who struggle with lupus every day. Knowledge also can rally people to our cause. With knowledge, they can take actions to increase awareness, raise money for research, and encourage government leaders to do everything they can to help people with lupus.

LUPUS UK is the only national registered charity supporting people with lupus and helping those being diagnosed. We offer information, resources and medical talks, a free helpline, regional support groups and an online forum with over 30,000 members and a grant program for research and welfare. **www.lupusuk.org.uk**

Saint Francis Hospice
Caring for you

Rated outstanding by the CQC, Saint Francis Hospice provides expert care for people in our community with palliative and end of life care needs.

We provide support and care for any person from any faith or cultural background diagnosed with a serious life-limiting illness and living in Havering, Barking and Dagenham, Redbridge, Brentwood or parts of West Essex. Saint Francis Hospice has been offering expert, compassionate advice and support for over 40 years.

Read some of the amazing stories on the Hospice website: **https://www.sfh.org.uk/news**

BEHIND THE GENE

Join us this May for Awareness Month: Behind the Gene

Throughout May, we'll be sharing powerful stories from those living with Huntington's, raising awareness, and taking action to ensure that no one faces this disease alone. With your support, we can provide vital care, advocacy, and hope for families affected. Huntington's disease is an illness caused by a faulty gene in your DNA - the biological 'instructions' you inherit which tell your cells what to do.

The symptoms of Huntington's disease vary widely between people. Even people in the same family may be affected differently. However, changes usually affect three main areas:

- Thinking - difficulties with memory and cognition such as planning
- Movement - movements may happen that you don't expect, while doing what you do want to do becomes more difficult
- Behaviour - changes in mood and personality

This year, we're shining a light on the real stories *Behind the Gene.*
For more details see: **https://www.hda.org.uk/**

Campaigning for a cure When Laura Kurtul lost her only child, six-year-old son Taylan from a brain tumour, she set up Fundraising Group, Tay's Tribe, to help fund research to find the treatments so desperately needed to improve outcomes for those facing a diagnosis. She called her MP and ended up with a pledge of support from the Prime Minister in the House of Commons for *"life-saving research"* into brain tumours.

Grieving mum prompts Prime Minister's pledge of support

Volunteers' Week in United Kingdom: June 2nd – 8th

Thousands of people across the country volunteer every year, enabling charities and voluntary organisations to help build stronger, more compassionate communities. Without volunteers, organisations simply couldn't do all the amazing things they do. NCVO is proud to be part of Volunteers' Week and will support organisations in thanking and celebrating their volunteers by sign-posting resources, offering guidance and shining a light on the huge difference volunteers make to their communities.

At NCVO, we're excited to get ready for Volunteers' Week 2025. Last year's 40th-anniversary celebrations were a brilliant chance to shine a light on the incredible and invaluable contributions volunteers make across the country, every single day, and we can't wait to do the same again this June. In 2025, volunteering in your community, or for causes close to your heart, will be more vital than ever as the charity and voluntary sector works to overcome some of the toughest challenges facing our society. We know how difficult it can be to find time or resources to give back, so to all those who volunteer, we want to say a big thank you for all you do to help build stronger, more compassionate communities. ***Sarah Elliott, CEO National Council for Voluntary Organisations (NCVO***
https://volunteersweek.org/england

The NHS is navigating multiple challenges. An ageing population, economic uncertainty, and unprecedented demand place significant pressure on the health service. The government has been clear that to meet these challenges – and to build a health and care system "fit for the future" – the NHS needs to "reform or die".

The Federation of Specialist Hospitals (FSH) **published a new report, The power of specialism in the future NHS.** which highlights the pivotal role of specialist hospitals in the future of the NHS. As the NHS embarks on a new 10-Year Plan, there is a unique opportunity for the government to harness the strengths of specialist hospitals to improve patient outcomes, drive innovation, and contribute to economic growth.

These recommendations and commitment to patient-centred innovation is welcome. Stronger partnerships between specialist hospitals and patients will help create more responsive services, improving both treatment and access to care.
FSH_-_Power_of_Specialism._DIGITAL.pdf


The power of specialism in the future NHS

FSH

Photo courtesy of The Walton Centre


Palliative and end of life care conference

Uncertainty with certainty: we can all make a difference and what's in it for me?

Date: Wednesday 21 May 2025
Time: 09:00 to 16:30
Where: Med002 lecture theatre
- Anglia Ruskin University,
Bishop Hall Lane, Chelmsford, CM1 1SQ

What to expect from the conference:

- Help us to understand that end of life is part of life and relevant to us all.
- Challenge ourselves to make that cultural shift where death and dying discussions are normalised in health and social care as well as in our communities
- How that can help the people we serve as well as us as professionals, our teams, our whole system.
- To understand our roles as citizens in society, supporting others living with life limiting conditions and in times of crisis and loss

Scan the QR code to register

Guy Peryer
Director of Education and Research

Dr Sarah Zaidi
PEoLC Clinical Lead, NHS Mid and South Essex

Dr Eva Lew
PEoLC Clinical Lead, NHS East of England region

Do you work with people nearing the end of their life?

Do you have a friend or relative with a life-limiting condition that you are supporting? Then this day conference at Anglia University might interest you.

The conference will help you understand that End of Life care is part of Life and relevant to us all. You'll discover how this approach can benefit both the people we serve and us as professionals, impacting our teams and the wider healthcare system. The day will also explore our roles as citizens in society, supporting others living with life limiting conditions in times of crisis and loss.

Book your place today to join colleagues committed to making a positive difference.

To register a place scan the QR code

National Down Syndrome Policy Group (NDSPG) held its first ever Advisory Group Summit on Thursday 27th March, 2025, in London, to raise issues affecting the DS community, Advocacy is very important to us at the Down Syndrome Research Foundation, as the rich knowledge that comes from lived experience is one of the greatest assets we can possibly have. We have worked to support the establishment of the Advisory Group since it's inception and lent our expertise to the project.

The group of 76 attendees included 29 adults with Down syndrome, 24 of which are Advisory Group ambassadors. They were joined by guests, speakers and participants from across the country, including Members of Parliament Andrew Cooper and Damien Hinds, who described it as "an excellent inaugural summit". It was a day of celebration, activism and future planning. The fantastic history and achievements of the Advisory Group were recalled, encouraging everyone present about the power of 'Experts by Experience', as James Carter describes himself.

Among the important agenda points covered, Advisory Group members put a spotlight on the following items:

- Discussing issues with the Down Syndrome Act Guidance 2022,
- Writing to MPs to ask them to step up and ask Stephen Kinnock, Secretary for Health and Social Care, to push for issuing robust guidance for the Down Syndrome Act.

Sessions on advising local Integrated Care Boards on health issues for people with Down syndrome, were presented by two members.

The Foundation continue to be thankful for the supportive voice of Dr Liam Fox for highlighting ongoing concerns with the development of the overdue #DownSyndromeAct Guidance. It is crucial this guidance is fit for purpose & reflects the specific needs of people with Down syndrome.
https://www.dsrf-uk.org

The ME Association's Count ME In survey ran for 3 months (May-July) in 2023 and received over 10,000 responses from the ME/CFS and Long Covid community. The survey was the largest and most ambitious of its kind conducted by the ME Association to gain a better understanding of the health and social care experiences of people affected by ME/CFS and Long Covid. Research findings are based on this survey, carried out by the ME Association and One Minute to Midnight.

Significant improvement in the diagnosis and care of myalgic encephalomyelitis (ME) and Long COVID is urgently needed across NHS and social care services, according to the new independent report created by the University of Exeter. Respondents reported significant delays in the diagnosis of ME and Long COVID, low satisfaction in specialist services, and a need for improved self-management resources and better-coordinated care. The report highlights wide dissatisfaction with NHS experiences. Only 6.9% of those with ME and 14.4% of those with Long COVID rated their experience as good to excellent. Many people faced significant delays in diagnosis, with some diagnosed after more than 10 years.

According to the report, published in **BMJ Open**, '***Understanding Symptom Clusters, Diagnosis, and Healthcare Experiences in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Long COVID: A Cross-Sectional Survey in the UK***', significant improvement in the diagnosis and care of myalgic encephalomyelitis (ME) and Long COVID is urgently needed across NHS and social care services.
BMJ published paper highlights key findings from The MEA's Count ME In survey - The ME Association

We are Undefeatable 5-in-5 is a movement supporting people with a range of long-term health conditions. They are offering new, achievable exercise support, called the 5-in-5 initiative. Start building small amounts of activity into your day with Five in Five, movements which you can do seated or standing for one minute each, to build a five minute workout. Go to weareundefeatable.co.uk/five-in-five for information.
WAU 5in5 Booklet V4

Dementia Action Week May 19th – 25th

is an awareness raising campaign. Each year, Alzheimer's Society works with individuals and organisations across the UK to encourage people to act on dementia. This year we are focussing on diagnosis and educating audiences on **the most common symptoms of dementia**.

Actor, presenter and writer Sir Tony Robinson joined Alzheimer's Society Director of Research and Innovation, Fiona Carragher, in the studio to record a very special episode of the Tony Robinson Cunning cast podcast. Listen to **Tony and Fiona's full interview here.** We will continue to raise awareness of the importance of an early diagnosis for people affected by dementia.

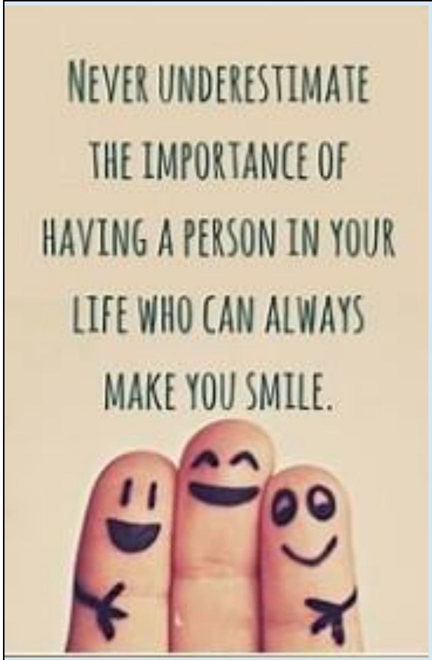
ATAXIA is the leading national charity in the UK for people affected by any type of ataxia. We fund research into finding treatments and cures, and offer advice, information and support to people affected by the condition. With only 10,000 people in the UK who are diagnosed, ataxia is a rare condition.

'Ataxia' is an umbrella term for a group of neurological disorders that affect balance, coordination and speech. There are many different types of ataxia that affect people in different ways. You can read about the different types of ataxia in our 'types of ataxia' section, or access a general overview of the condition in our **"Ataxia: what's that?' leaflet**. A brief introduction to 'What is ataxia?' can be found **here.** **https://www.ataxia.org.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/uoe-neurorehab-research-brown-bags-b8sww61e47aa22a8**

Please register here on the **online form** **or** email Katie Chadd: **katie.chadd@essex.ac.uk**



National Smile Month: May 16th - June 15th

We certainly need something to smile about in these days of trade tariffs, rises in taxes, the increase in our basic daily bills for food and heating and the upheaval of the NHS!

National Smile month is a charity campaign all about championing the benefits of having good oral health, raising awareness of important health issues, and promoting the value of a healthy smile.

However, what a difference a smile makes! It is reassuring, makes one feel the smiler is confident in what they do and that they are here to help you as best they can. So, come on everyone, let's smile in May! Even if you are on the phone to someone with a neurological condition, you should smile. It makes everyone feel better and the outcome for everyone, staff and patient alike is so much better!

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

'Today, give a stranger one of your smiles. It might be the only sunshine they see all day.'
H. Jackson Brown, Jr.

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

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