

# Connexions

December 2024  
Bulletin No.8

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*

## HOT OFF THE PRESS!

**UK Government launches first-ever forum to address gaps in treatment and care for people affected by neurological conditions.**

Today (Thursday November 28<sup>th</sup> 2024) Andrew Gwynne MP, Parliamentary Under-Secretary of State at the Department of Health and Social Care, has announced a new UK-wide forum will be set up to find ways to improve care and support for people affected by neurological conditions.

The announcement follows a long-standing campaign led by The Neurological Alliance together with The Neurological Alliance of Scotland, Wales Neurological Alliance and the Northern Ireland Neurological Charities Alliance and supported by over 100 organisations and more than 19,000 people.

The “Back The 1 in 6” campaign called on UK Governments to establish a Neuro Taskforce to address key challenges facing people affected by neurological conditions, including delays to treatment and care, a lack of mental health and wellbeing support and insufficient information at the point of diagnosis. The campaign was underpinned by the experiences of over 8,500 people who responded to My Neuro Survey, the largest neurological patient experience survey in the UK.

The forum will unite clinical leaders, organisations, and people with lived experience of neurological conditions to tackle shared challenges. Shaped by those it serves, the forum will aim to drive real progress in areas where UK-wide collaboration is most impactful. It will aim to address unwarranted variation in access to care across the country, and drive person-centred care.

For more information about The Neurological Alliance and the #BackThe1in6 campaign, visit <https://www.neural.org.uk/>

**All of the team at Essex Neurology Network wish you:  
A Very Happy Christmas!**



Charity Christmas cards are still available online from the following groups:  
Alzheimer's Society, Brains Trust, Brain Tumour Research, Carers UK, Dementia UK,  
Epilepsy Action, GAIN Charity, Hospices UK, ME Association, MIND, MND Association, MS  
Society, National Autistic Society, Scope & many other charities  
Go to: <https://cardsforcharity.co.uk>



### This Christmas, Help Young Carer Leila Be A Kid Again

Introducing Leila - a 13 year-old who faces responsibilities well beyond her years – caring for her blind father, supporting her non-English-speaking mother, and looking after her younger brother. Every day, she juggles the stresses of managing a multitude of household tasks and complex family needs, such as translating medical letters, taking phone calls, making meals, and administering medicines, all the while missing out on the joys of childhood. Your support can give children like Leila a much-needed break, allowing them to enjoy the simple joy of being a child ... **And this Christmas, you can make that magic happen again!**  
**Carers Trust : <https://carers.org>**



   
**Christmas shopping  
= free funding!**

### Raise Funds This Christmas

Did you know 70% of shoppers will do their Christmas shopping online this year? And did you know this shopping can easily turn into funding for your organisation? 8,000 popular online shops including Amazon.co.uk, eBay, Argos, Boots, Lakeland, John Lewis, Currys, Etsy, M&S, Not on the High Street, Sainsburys, Waterstones, Moonpig and 8,000 other businesses will donate money to you whenever someone connected to your organisation shops with them, at no extra cost to the shopper. To take advantage of this festive fundraising idea, register your voluntary organisation, charity, social enterprise or CIC with [Register your good cause | easyfundraising](#)



### Searching for the Perfect Gift?

The NTUK shop has everything you need to make this Christmas special! From festive teddies to our best-selling Christmas cards, all you have to worry about is the wrapping paper. And remember, every pound spent goes right back into supporting essential services for the NF community.

Make it a Christmas to remember with a gift that gives back! [Nerve Tumours UK](#)



### It's beginning to look like Christmas!

**The Stroke Association Christmas shop is now open!** Within the festive range you will find gift wrap, advent calendars and money wallets along with beautiful card designs for you to send

to your loved ones.

This year you can purchase 'Snow Bear', an extra special card designed by our 2024 Christmas card competition winner Michelle Carter. Michelle was just 30 years old and pregnant with her first child when she had a stroke in 2014, leaving her grieving the person she had been/was before and trying to accept the new person she had become. Two years after her stroke, Michelle rekindled her love of painting and drawing. 'To cope with my recurring headaches after my stroke, I turned to art which helps bring me a sense of peace'. <https://shop.stroke.org.uk/>



### Your Christmas donation could help people like Eoin

When Eoin was diagnosed with MND, it was devastating. But his practical side soon took over and he decided to bank his voice. Eoin couldn't bear the thought that one day he wouldn't be able to communicate with his family - and it was really important to them all that his Irish accent was captured. It's distinctive to him, and he wanted his family to be able to hear his voice, filled with love for them, for many years to come.

"Even though MND took my voice, I can still read a festive story to my children." <https://www.mndassociation.org>





## Spread some festive cheer with a Headway Essex charity Christmas card.

Explore their wonderful range of charity Christmas card designs from traditional, religious, fun and much more!  
All cards are £5.00 for a pack of 10 of the same design, inclusive of postage and packing.

<https://www.headwayessex.org.uk/i-want-to-help/christmas-cards>

## Join in Christmas Jumper Day for Ataxia UK!

This December, host your own Christmas Jumper Day with your colleagues! Whether you're working from home, or back in the office full time, everyone can get in on the fun! Simply pick your day and let your employers know what you're planning to do. Once you've got the okay to go ahead with your Christmas Jumper Day, let your colleagues know to bring some cash and their finest, festive jumper. You can stick to just the snazzy jumpers, or you could get busy with a bake sale, or Christmas raffle to really get going with your fundraising. <https://www.ataxia.org.uk/christmas-jumper-day>



The Government has recently launched [change.nhs.uk](https://change.nhs.uk) a consultation to gather public and organisational feedback on suggested changes to the NHS. The responses patients and organisations give to this consultation will help to form the new 10-Year Health Plan - part of the Government's health mission to build a health service fit for the future.



THE  
**NEUROLOGICAL  
ALLIANCE**

**The 10-year Health Plan for England** Following the launch (see above) of the Government's [consultation](#) on the future of the health service, we've been speaking to members about our collective priorities to ensure the NHS 10-Year Health Plan for England delivers for people affected by neurological conditions.

Following an urgent member meeting, the NA put together a [draft longlist of proposed actions](#) to ensure the plan improves services and support for the neurological community now and in the future. [Download our draft actions for the 10-Year Plan](#)

Feedback on actions proposed in the document was welcomed back in November on how health and care services are delivered, bringing care closer to home, moving from analogue to digital and placing a greater emphasis on prevention.

**The Law Commissioners** are conducting a review of the legal framework governing social care for disabled children in England to ensure that the law is fair, modern and accessible, allowing children with disabilities to access the support they need. Responses need to be sent in by January 20<sup>th</sup> 2025. The consultation paper is available [here](#) and a summary can be accessed [here](#). Where possible, it would be helpful if this online form was used: <https://consult.justice.gov.uk/law-commission/disabled-childrens-social-care/>. However, we are happy to accept comments in other formats. If you would like a response form in word format, do email us to request one. Please send your response: By email to: [dcsc@lawcommission.gov.uk](mailto:dcsc@lawcommission.gov.uk) OR by post to: Disabled Children's Social Care Team, Law Commission, 1st Floor, Tower, 52 Queen Anne's Gate, London, SW1H 9AG.

## 7 MEPs participate in meeting on Brain Health & Neurological Conditions

On November 12, 2024, the first post-election meeting of the MEP Interest Group on Brain Health and Neurological Conditions took place at the European Parliament, Brussels. Entitled '*Invisible Issues: Bridging the gap between the perception of neurological conditions and their true impact*', the event's main objective was to discuss the challenges of living with a neurological condition, the impact this has on the individuals and families affected, the impact on education and employment and to highlight where we need to do better in policy development and implementation.

[Click here to read the meeting report.](#)



**Brain Injury Survivors** For twenty-years, Dr Alex Street has worked with brain injury survivors to help cognitive, speech and sensorimotor recovery, psychological and emotional wellbeing, usually in a conjoint, interdisciplinary or multidisciplinary capacity. This is done using acoustic instruments, iPads with touchscreen instruments & other technology, music improvisation, songwriting, recording & music listening, as well as talking – about the processes & products in the context of the injury. The people I work with actively sing or play instruments, and plan, organise, negotiate & make decisions about music compositions or the direction of improvisations. Structure in the music and sessions varies, depending on the objective; if it is to improve focused, sustained & selective attention to help with speech recovery (aphasia, dyspraxia, cognitive communication difficulty), then rhythmic patterns of increasing complexity are copied, leading to vocal sound copying, words, phrases & songs, all of which targets specific attention & executive processes & facilitates massed & rewarding practice. For addressing identity issues and coming to terms, improvising and/or songwriting, which also addresses executive skills, can be effective, motivating and creative.

Past research projects have included implementation in acute & post-acute neurorehabilitation where the services were set up & evaluated and included training other clinicians how to use music equipment & structures in goal-directed ways, & home-based interventions for arm hemiparesis. Current studies include delivery of 15 sessions for arm/hand rehabilitation over three-weeks in stroke survivors' homes & measuring changes in motor and cognitive activity using EEG; developing a music listening protocol for fatigue management (associated symptoms including pain and mood) in post-acute neurorehab; a bespoke touchscreen musical instrument app for arm/hand rehabilitation. Ongoing patient, carer and public involvement work plays a key part in project planning & delivery, & clinical work informs on progression into real-world applications. *Dr Alex Street - Senior Research Fellow at the Cambridge Institute for Music Therapy Research, Anglia Ruskin University*



## Essex Frontline referral and signposting platform comes to Tendring

A new digital referral and signposting platform is being launched initially in Tendring by the North East Essex Health and Wellbeing Alliance. The Essex Frontline platform provides an up-to-date library of local health and wellbeing services for frontline workers and the public to quickly find details of local health and wellbeing services and to contact these through call back and referral options. [Essex Frontline](#) was launched on November 18th 2024.

Tendring will have its own Frontline website - [Tendring Frontline](#), which will enable services to refer and signpost to multiple partners securely, safely and quickly.

Local health and wellbeing organisations are actively encouraged to use this FREE new platform to:

- Promote your service
- Find other local help
- Make quick and secure referrals to partner organisations
- And more!

### How to Register

Registering your service is really easy. Our [‘How to Register’ video](#) walks you through.

If you prefer the friendly human approach, or would like to see a Frontline demo first, we host live drop-in sessions, twice a week, via Teams, where we show you Frontline and answer your questions. A session lasts about 20 minutes and there's no need to book ahead. We would love to meet you! If you would like more information, please call or email us:

01799 618 855 / [info@frontlinereferrals.org.uk](mailto:info@frontlinereferrals.org.uk)





## Christmas customs through the ages

**Mulled wine** is a lot older than you think. Created by the Romans, it dates all the way back to the 2nd century. As the Romans conquered Europe, their love of mulled wine spread. It's always been thought that mixing wine with spices and fruit is good for your health and a way to stave off illness. However, it wasn't until the 1890s that mulled wine became associated with Christmas.

It's thought that **singing carols** for the birth of Christ date back to the 4<sup>th</sup> and 5<sup>th</sup> centuries, whilst the first **Christmas market** originated in Germany at Dresden's *Striezelmarkt*, first held in 1434.

The British **Christmas tradition of sending cards** dates back to 1843, when a gentleman named Sir Henry Cole didn't have time to send personal messages, so hired an artist called John Calcott Horsley to design him a card, which he could send to lots of people.

**The mince pie** represents the crib in which baby Jesus lay, with the pastry lid representing the cover over him. The 3 snips are for the three kings and the mincemeat for the gold, frankincense and myrrh.

**Christmas or plum pudding** as it's also known, started life off as 'frumenty'. This was a dish made of beef and mutton with currants, raisins, prunes, spices and wine. By 1595, frumenty slowly changed into plum pudding with eggs and breadcrumbs to make it more of a cake.

**Ukrainian Christmas trees** are traditionally decorated with a fake spider and web. The custom, which is said to bring good luck, stems from an old wives' tale about a poor woman who could not afford to decorate her tree, but woke up on Christmas morning to find a spider had covered it in a glittering web.

The tradition of **hanging holly and mistletoe** in the house goes back to the times of the ancient Druids, who thought that fairies and elves lived in the greenery because it stayed green all winter. They believed they had mystical powers, which brought good luck to the household and warded off evil spirits.



## True Stories

Being in hospital at Christmas is no fun, although everyone tries hard to make it as good as possible, sometimes with carol singers visiting or even Santa making an appearance. Last year, an elderly lady was in a local hospital recovering from planned major surgery. She could barely move in bed and had various tubes, drips and catheters attached to her. Sleep was difficult especially at night time, when all was quiet except for the regular beeps and sounds of a busy ward. With nobody nearby to talk to and many anxious thoughts running through her head, the night ahead looked bleak and lonely. In the early hours of the morning a young medic appeared at her bedside to do some checks and they talked for a while, sharing news of themselves and their families at Christmas. After he left her, several times he peeped out of the curtains around other patients' beds, giving her a cheeky wave and a thumbs up, making her smile. That Christmas night she was able to fall asleep with happy thoughts!

*If you have a story about how someone went out of their way to do something special to help you, or about someone with a neurological condition that you know, 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 January 10th. Please send to [essexneuronetwork@gmail.com](mailto:essexneuronetwork@gmail.com)**

