



## CHRISTMAS CHEERS ALL ROUND

### Christmas Panto



Christmas again saw nearly 40 of us visiting the panto at The Cliffs. It was great fun, with loads of audience participation. Rylan, in amazing costumes, effortlessly commanded the stage, full of Essex banter, warmth and wonderful adlibs, whilst being constantly interrupted by his mother's phone calls! Grace and Elliott were even lucky enough to meet him at the stage door after the show.

The Cliffs are undergoing refurbishment so had to cancel our restaurant meal. Instead, they allowed us to use one of their function rooms free of charge, staffed the bar and let us bring in a wonderful buffet lunch. It worked really well, with plenty of time to chat, indulge in the excellent food and wear silly paper hats from the crackers.

Thanks are especially due to Debbie, ably assisted by Rowan, for doing all the booking, liaising with the Cliffs and sourcing the food. Let's hope The Cliffs refurbishment includes a larger, more reliable lift in time for next Christmas!

Those who couldn't get to the panto received a gift of flowers, chocolates or a shopping voucher and Barry, Gill and Pat had a great time meeting as many of you as possible when they did the deliveries.

### Christmas Quiz

Staff at **Essex and Suffolk Water** raised over £2,000 for multiple charities during their Christmas Quiz / Raffle on Tuesday 17th December. Hundreds of colleagues got involved, and a live singer even joined in the proceedings. **£725** of the money raised was donated to MNDA in memory of Charlie Marden, a much loved and respected colleague at the company.



### Thames Bridge Trek

Earlier in the year **Barry** and **Stuart** have raised **£1,070** walking 25km over 15 London Bridges on 14th September. They're already building a team with other members of **Runwell Hospital Bowls club** for next year.

Fancy joining them? Please contact Barry if you do.  
[sessexmnd.brm@gmail.com](mailto:sessexmnd.brm@gmail.com)



# Events to Come

## AGM

Our next AGM will take place on  
**Saturday 1st March 11:30 to 15:30**  
at **St Luke's hospice.**

Same format as last year with a presentation of our activities this past year, a guest speaker, light lunch and free massages available.



## Walk to D'feet

The 2025 edition of our annual fund raising walk is scheduled for

**Sunday 11th May.**

More information to follow as we await Southend Council's decision regarding our application and our route.

Please check our facebook page or website where we'll post the details once confirmed.



**JOIN  
OUR  
TEAM**

We would love to have more people volunteering as Association Visitors especially if they live in South West Essex. One needs good listening and communication skills to help support those living with MND and those closest to them, either by phone calls, emails or home visits. The Association provides really good training. If you need more information contact one of our existing AVs or look at [Association visitors](#) | [MND Association](#).

## MEET UP?

### Meeting Dates

**Drop in meetings 2-4pm**

**The hospices kindly let us use their lovely rooms for our get togethers. Chat and make friends. We will supply the food and drinks.**

Friday 7th February- Fair Havens

Friday 4th April - Fair Havens

Saturday 3rd May- St Luke's

Friday 6th June - Fair Havens

Saturday 5th July- St Luke's

Please contact Pat for

more information

[sessexmnd.py@gmail.com](mailto:sessexmnd.py@gmail.com)



### Recently Diagnosed Group

3rd Friday of the month via Zoom 2pm.

Allows all affected people to ask any question and find out about available support.

17th January/ 21st February / 21st March /  
16th May / 20th June

Please contact Pat or MND Connect



### South East Region

#### Carers' Coffee and Chat

Evenings: Last Wednesday of the month via Zoom 6.30pm.

29th January/ 26th February / 26th March

30th April / 28th May / 25th June

Daytime: 1st Tuesday of the month via Zoom 11am

4th February/ 4th March / 1st April

6th May / 3rd June / 1st July

Please contact Pat or MND Connect

### South East Region

#### Peer Support Group

3rd Tuesday of the month via Zoom 11am.

21st January/ 18th February / 18th March

15th April/ 20th May/ 17th June

Please contact Pat or MND Connect

### Veteran's Group

4th Wednesday of the month via Zoom 2.30pm.

22nd January/ 26th February / 26th March /

23rd April / 28th May / 25th June

Please contact Dawn Pond for details  
[dawn.pond@mndassociation.org](mailto:dawn.pond@mndassociation.org)

Other groups available on MND Association website.  
Please scan above QR code.



## Research Update

### New online resource for people considering tracheostomy ventilation

Researchers from the University of Nottingham, funded by the MND Association, have developed an online resource for people with MND who are thinking about having tracheostomy ventilation (a tube fitted into the windpipe to help breathing).

The researchers interviewed people with MND who use tracheostomy ventilation and family members who support or have supported someone with MND to use it. This helped them to find out more about how they came to use this type of ventilation, its benefits and challenges, the care needed to support everyday life and the impact of tracheostomy ventilation on their quality of life.

These interviews have been used to build an online resource of information for people with MND who are considering tracheostomy ventilation so that they can better understand what is involved and what it will be like.



### Prescribe Life Campaign update: Tofersen Moves Closer to Approval



On Monday 18th October, the National Institute for Health and Care Excellence (NICE) announced that they will evaluate Tofersen using the Highly Specialised Technology Framework. This provides Tofersen with the best chance of NHS approval, showcasing progress in the right direction for the SOD-1 MND community.

Over the last three weeks, staff, supporters and the MND community came together to help achieve this milestone. Our #PrescribeLife petition gained an impressive 15,000 signatures and attracted national media attention, highlighting the urgent need to evaluate tofersen correctly.

We are extremely thankful for all the support we received across our community.

Let's keep the momentum going - please share this update with your networks and help raise awareness about this major step forward.



## Mate's Nutty Debates

Some folks in Southend have set up a new **WhatsApp group** just for those local people living with MND. They say "we're hoping for a nice intimate friendly group where we can have a giggle and be a bit more sociable and get to know each other better". They are also planning a get together on Friday 17th January, 12.30pm, at The Saxon King pub, next to Fair Havens Hospice. If you'd like to be part of this contact **Sean** on **07814 225155** . Just sending a text is fine.



### Bio Bidet 1000 and freestanding shower screen.

One of our members is offering these free to anyone who could make good use of them. The Bidet attachment works with automatic and remote control settings, can wash clean and

dry the user, and fits most toilet pans. If you are interested contact Pat Ahlquist who will put you in touch. [sessexmnd.py@gmail.com](mailto:sessexmnd.py@gmail.com)

#### Pat Ahlquist

Branch Contact  
[sessexmnd.py@gmail.com](mailto:sessexmnd.py@gmail.com)  
07383 568 585

#### Chloe Rich

Community Support Coordinator  
[chloe.rich@mndassociation.org](mailto:chloe.rich@mndassociation.org)  
[www.mndsouthsessex.org](http://www.mndsouthsessex.org)

**mndconnect**  
**0808 802 6262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)



@MNDsessex



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## Warm Welcome!

We now have a new MNDA Community Support Coordinator in the person of Chloe Rich who was previously a Project Manager in the Hospice sector. Chloe is also a trustee and volunteer at her local Autism charity in Harlow and on weekends she runs an art therapy group for neurodivergent young women, as well as transgender and non-binary individuals.



### JustGiving Page

Scan attached QR code to access our JustGiving page for MNDA South Essex branch and use it for all your fund raising events



## WHO'S WHO in your BRANCH

**Stevan Wing:** President

**Philippe Udrzal:** Chair/committee

**Pat Ahlquist :** Vice Chair/committee

**Rowan Harvey :** Treasurer/committee

**Debbie Darke :** Secretary/committee

**Marianne Morgan:** committee

**Kevin Watts :** X/committee

**Michelle Bingham :** Walk to D'feet/committee

**Gill Gibson :** committee

**Barry Mizen :** web master/committee

### Association Visitors

**Pat Ahlquist :** branch contact

**Gill Gibson**

**Barry Mizen**

**Community Support Coordinator**  
**Chloe Rich**