

# YOU, ME AND MND

## Exeter and East Devon Branch newsletter



Dear members, friends, MND family,

we have reached a period in time where nothing is certain, apart from family support, the MND extended family included. At the Exeter and East Devon Branch, we will continue to support you remotely. Our aim is to always do our best whenever we can to assist you.

Looking back over the last year, we connected with many of our members through Awareness and Fundraising events. These were much enjoyed by the entire branch, it was so lovely to see you, those who care for you, family and be able to say hello.

Notably, many of you gifted your support for our first big Awareness event 'Walk to D' Feet at Haldon Woods. We were fortunate to have the support of the Lord Mayor of Exeter Peter Holland and his wife Jackie, we were also joined by the marvellous Exmouth Town Crier, Roger Bourgain setting us off in style. Thank you to all who facilitated this.

The committee worked well together, with everyone pitching in, our new committee members taking up posts and assisting longstanding committee members with urgent tasks on the day. A wonderful walk through the woods was followed by a delicious Devonian Cream Tea supplied by Haldon Ridge Cafe, thank you to both Haldon Forests and Ridge Cafe for ensuring our day was much enjoyed by all.

Our ongoing engagement and support with Exeter University has helped to create communication platforms, such as this Newsletter and supported events to help make them a reality. Collections and Awareness at Bicton Park during the horse trials

proved popular. Whilst attending local country fairs with the Tombola was a huge success. We have also been gifted huge sums for the branch from Exmouth's Tri Hards, who invited the committee to their fundraiser ball. A big thank you too to all those who generously gift collections, raise our profile locally and support us throughout the year.

A big thank you too, to the staff at Peninsula Medical School and our student volunteers we were invited again for the second year to the Undergraduate Medical School Student Conference, organised by our students.

Two of our AV committee members were able to meet with students, informing them about MND and how we help, discussing complexities of life with MND is vital to recognising it as a clinician in the future. Exeter and East Devon Branch would like to extend deepest gratitude to Exeter University, Staff and our Student Volunteers.

Finally, we sincerely hope you are all keeping yourselves indoors and that you have the support around that you need. It's a tough time for you. Please do not hesitate to contact us if you need support we can discuss via telephone/ FaceTime and Skype as per current regulations.

Wishing you all safety and support during the oncoming months.

Elizabeth Cargill

Chair of the East Devon and Exeter Branch

### INAUGURAL WALK TO D'FEET - HALDON FOREST 2019

Exeter and East Devon Branch of the MND Association offer a huge thank you and an update for all who supported our Haldon Forest walk on 6 Oct 2019.

The day began with the arrival of our trusted blue army of committee members and volunteers swiftly assisting with chosen tasks. The Ridge Café at Haldon forest and Haldon's rangers offered great support to ensure everything ran smoothly for the arrival of the Lord Mayor and Lady Mayoress of Exeter, Peter and Jackie Holland. Exmouth's finest Town Crier, Roger Bourgein arrived early, keeping everyone entertained, engaging in conversation with visitors and early arrivals.

Branch President and Consultant Neurologist, Dr Timothy Harrower, joined by his family, led the walk with the Lord Mayor and Lady Mayoress who were delighted to have former Royal Marine, Brian Mackay arrive to lead, joined by carer Lyn, and daughter, Lisa Findel-Hawkins of Exmouth's Tri Hards.

Our MND family, enjoyed the best of Haldon Forest. The stunning Discovery trail meandered leisurely through a scenic route and ended on a high note with a scrumptious cream tea provided by the wonderful Ridge Café.

Former Royal Marine, Brian Mackay, expresses gratitude; he and his carer Lyn had a ball at the walk. They were joined by daughter Lisa who was "delighted the sun was shining, lifting everyone's spirits and uplifted to see so many smiling faces of young children, dogs who joined in, all followed by a superb cream tea. A truly delightful day, helping to raise more awareness of MND."

Dr. Timothy Harrower recounts the "great day for the MND family, with the help of fine weather, excellent support rewarding the hard work of our local volunteers and organising committee for the MNDA. This all encouraged the Mayor to pledge official support in the long-term. Thanks to all who contributed to making a great success of the day".

Our Association Visitor Cynthia Hopkins recalls "a wonderful day very well supported, even by strangers. It was a great community effort to raise awareness of this terrible disease".

As the Chair, I express sincere gratitude on behalf of Exeter and East Devon Branch to all who supported our day. Our devoted committee all worked fantastically well together as a team for our first big local event. We truly appreciate your support for our local branch. Welcome to our new volunteers and passing newcomers who joined supporting our event with our MND family members. Thanks to each and every one of you who made it a truly special, extensive family occasion.

Treasured memories were captured on film by branch volunteer members Rebekah and Johnathan @ rebekahhortonprintedpoetry and

@Johnathanpalfrey. Find out more at https://www.rebekahhorton.com.

Photography from the event can be found at bit.ly/MNDAwalk2019.

#### **ACT TO ADAPT - CAN YOU HELP?**

The MND Association's Act To Adapt campaign aims to raise awareness of the issues people with MND face in getting home adaptations and call on councils across England and Wales and the Northern Ireland Housing Executive, to implement the Act to Adapt report recommendations on housing adaptations for people with MND.

You can help us launch the campaign by having your say now. If you are **living with MND** and have experience of accessing home adaptations, you can contribute to the campaign launch by having your say now. If you **don't have personal experience** of accessing home adaptations, we want you to have a say too. Whether you're a campaign supporter, professional or councillor, simply share a short message about your vision for home adaptations for people with MND and why this matters to you.

By sharing your message or experience, you will help raise awareness and inspire other supporters and decision makers to take action to help make home adaptations easier for people with MND.

You can have your say at www.mndassociation. org/act-to-adapt-have-your-say.



#### **SALIVA MANAGEMENT**

Written by Tracy Thomas, Devon Lead Nurse Specialist in MND

For many people with MND, the issue of excess saliva is a big problem. It is important to remember that everyone produces over 1.5 litres of saliva every day, but people with MND may be struggling to swallow that volume, hence why you can find yourself drooling.

Unfortunately, the problem is that many of the drugs we use do not prevent saliva being produced; instead they simply dry up what is there, so you can be left with very thick, dry saliva that is hard to swallow and sticks in your throat.

We use drugs like Atropine eye drops (administered under your tongue), a hyoscine patch that is placed behind your ear and tablets such as Glycopyrroium, and Buscopan. All these medications have some side effects, e.g. the patch behind your ear can make you feel woozy, sleepy and slightly uncoordinated.

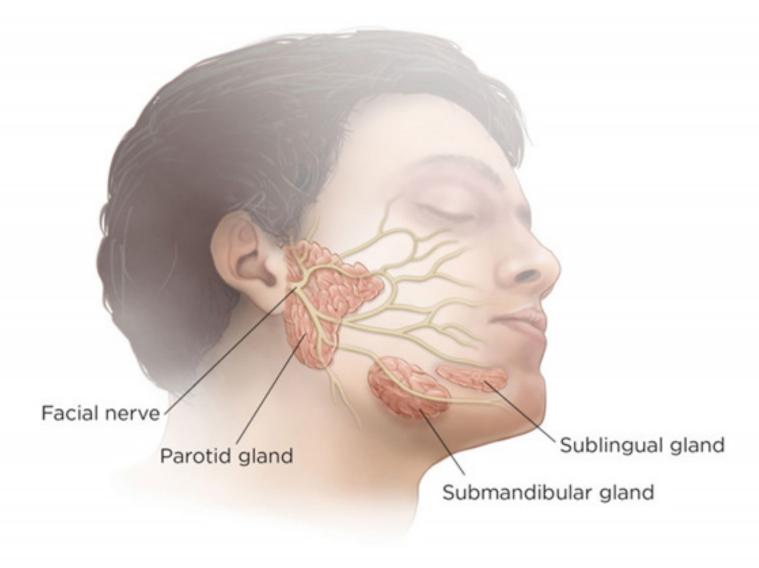
An alternative approach is using the botulinum toxin, which is injected into the salivary glands to prevent them from producing saliva. As we have six main salivary glands, we can inject into two or four and still leave enough glands to produce sufficient saliva to keep your mouth from becoming too dry. It sounds a little daunting to have injections in salivary glands, but it's a quick and relatively painless procedure that is done in our outpatient clinic.

The salivary glands are quite close to the skin, so the needle used is very small. There may be a little bruising or bleeding afterwards (but this is rare) and you get none of the side effects the other drugs cause, so many people like it. The other good news is it only has to be done every three months. Nowadays drugs and toxins are not the only way to help manage excess saliva. Think about things like positioning. How you sit or sleep will impact this. So, imagine if you sleep in an upright position or on your back, where the saliva tends to collect in mouth and trickle down your throat, causing coughs and splutters. Far better to sleep on your side in a slightly more upright position, bit with more pillows then in the picture. This way saliva drains out of your mouth. It helps to have a towel nearby.

Another helpful tip is to avoid consuming too much dairy produce, as this thickens saliva. Drink plenty of fluids, as a dry mouth will also thicken saliva. Tomato juice is thought to reduce the amount of saliva you produce, as are ginger and lemon. Pineapple is great for making very thick saliva thinner if you have a very dry mouth. Artificial saliva can also help if your mouth is too dry after treatment.

We also have equipment that can help manage your excess saliva, such as a suction machine. The most important thing to remember is that we can do a lot of things to help with this problem, but it is not always something we can completely prevent, so it is about living with a level that is manageable for you.

We advise you to contact the **Tracy Thomas**, Lead Nurse Specialist at the MND team in Devon on **01752 436759** if you have any issues with excess saliva and we can discuss your issues and if needed arrange the things mentioned in this article.



#### Dr Timothy Harrower on dealing with saliva management in MND

In Motor Neuron Disease, swallowing can be affected which will mean that getting rid of this large amount of fluid becomes quite a problem. The saliva then emerges as drooling (or from a medical terminology point of view we would call it sialorrhoea).

There are many ways of trying to cope with this unwanted fluid and it does need quite a comprehensive approach to thinking about dealing with the fluid and as part of any motor neuron disease clinical appointment which should look at this area in a great deal of detail and consider what can be done before embarking upon simply prescribing medication this broad-spectrum approach is outlined in now management protocol that we have produced for the multidisciplinary clinic meetings for motor neuron disease that we hold across been intra but for our area this would be at the Mardon Neuro Rehabilitation Centre on a Wednesday afternoon.

Some of the areas that need to be considered before embarking on any medication are as follows and will hopefully be discussed in this clinic appointment:

- Avoidance of foods/fluids that increase salivationcitrus fruits, heavily spiced foods, bacon
- Advise use of toothpaste with anti-foaming agent
- Suggest suction toothbrushes/maintain dental hygiene
- Consider position to reduce drooling with bed positions, recliner chairs, tilting wheelchair
- Use of barrier creams to protect skin around mouth/use muslin squares instead of tissues
- Consider brace/collars to raise head (collars are not well tolerated in people with MND
- Refer to Speech and language for full assessment of swallow function
- Refer to respiratory team for full assessment of cough.
- Consider suction machine.

However if I were to consider what medications could be used (this was the intended brief about my contribution for this month's news letter) the following details about medications need to be considered. Firstly I would have to consider the nature of the saliva that needs to be dealt with.

This saliva can either be quite liquidy (non-viscous) much more like water but sometimes given the saliva can become very thickened (more viscous-thickened and often more sticky).

### Dealing with too much liquid saliva (non-sticky non viscous)

If the saliva is simply very liquid and it very voluminous then there are number of steps that we can use medically to try and dry up the saliva by turning off the production line i.e. by trying to instruct this salivary glands to produce less saliva.

Here we have a choice of options including using a patch which has advantage in that you do not have to swallow this medication, using again eyedrops which can be dropped into the mouth to dry up secretions in the mouth area and then some tablets.

However more recently the use of Botulinum Toxin Type Ahas become mandated as probably first-line treatment and is in fact fully funded by the National Health Service. One particular form of Botulinum Toxin Type A - called Xeomin has specifically been licensed for trying to deal with this problem. Xeomin has to be injected directly into the salivary glands. I would normally target the 4 main saliva glands and sometimes to make sure that we get the Botulinum Toxin Type A (Xeomin) into the specific gland I may need to use ultrasound guidance to visualise the salivary gland and inject directly visualised target gland. Sometimes though there is no need to have the use of the ultrasound if the gland is where you would an anatomically normally expect it to be and injections can just be undertaken without ultrasound guidance.

These injections are generally done every 3 months as that is how long the injections can last and therefore without any generalised side effects other than of course at the time, risk of pain (because of the fact that toxin has to be injected through and very fine needle), bleeding, bruising it has now become the main and first-line step in managing this problem.

The various options your doctor or your treating team might well resort to are as follows:

**Glycopyrrolate**, which is available in the form of tablets, suspension and ampoules. Thus this option can be used via the PEG tube if that has been required. But similarly the tablet all the suspension can be very helpful in limiting the saliva production. The recommended dosage if using the tablets would be one or two tablets three times a day.

Amitriptyline, which is a well-known antidepressant at much higher doses say for example 150-200 mg can be used at a much lower dose as its main side effect is in fact drying up of secretions and it is in this setting that we would want to use it for managing the drooling. Generally speaking 10 mg is all that is required and this can be used once at night. It can cause sedation which in fact if somebody struggling to sleep this can be very helpful in improving sleep as well. If 10 mg is not proving to be effective the dosage can be gently pushed up as required but usually about 20 mg is all that is required.

**Hyoscine patches** (Buscopan) are a further option. As they are patches they do not need to be swallowed

and therefore can be conceivably a very easy option to start with. However there are limits on when it can be used for example it should not be used if somebody suffers from glaucoma and it can cause constipation and at times confusion. There also Hyoscine tablets and these can be used if swallowing is not a problem probably at 10-20 mg tablets 3 times a day. One solitary is generally acquired on a once a day basis and left in place for 24 hr.

**Atropine eyedrops** 1-2 drops into the mouth at the appropriate time can be used if the drooling is intermittent or person only concerned about treatment at key times. The drops are short acting and because they are dropped into the mouth a work on the saliva glands immediately and generally speaking are not absorbed into the body and therefore have minimal systemic side effects.

### Dealing with saliva if it is too thick and sticky (viscous saliva)

If on the other hand the saliva becomes too thickened it becomes very difficult to clear particularly if it goes down the windpipe. Sometimes it is better to convert the thickened fluid into a more liquid type of fluid which is sometimes easier to swallow. So in essence 1 of the 1st things we have to consider is whether treatment should revolve around changing the nature of the saliva. To make fluid less thick we can use carbocisteine or Pilocarpine 4% eye drops (administered into the mouth):

Carbocisteine may help break down mucoid secretions but more usually used with bronchial secretions. They can cause gastric ulceration, so avoid in people with gastric ulceration & use with PPI if appropriate. It is available as suspension (250mg/5mls) and capsules 375mg (but capsules are large to swallow) the usual dosage is 2 tablets taken three times a day. But maybe an extra one can be used if the drooling is very severe at a particular time.

**Pilocarpine** 4% eye drops - often used for dry mouth in oral cancers. Can provide more moisture to saliva, but beware not then causing excessive salivation. Can be helpful at meal times, as saliva needed to chew effectively. Should be avoided in people with asthma, IBS & cardiac disease. Side effects can include flushing and palpitations. Can take up to 12 weeks to work properly, usually we would advise using 1-4 drops three times a day with meals.

Before starting a medication it is worthwhile considering the following aspects which may go along to help with thickened and sticky secretion and are worthwhile addressing:

• Ensure adequate hydration, chilled cold drinks may help if drinking orally

- Maintain rigorous oral hygiene & monitor for oral thrush
- Use of pineapple or papaya juice/chunks (as safe) to break up thick secretions
- Boiled sweets and chewing gum can help if SLT confident of safety
- Avoid dairy, caffeine, alcohol and high sugar intake
- Avoid alcohol based mouth wash
- Use of artificial saliva sprays (better than gels)
- Steam inhalation and nebulisers can moisten secretions
- Liaise with respiratory team for review of cough
- Use of breath stacking/manual assisted cough or cough assist if appropriate
- A small amount of butter in the mouth can help loosen adhered secretions, if safe from swallow aspect.
- Using humidification on Non Invasive ventilation

We have so far not needed to use radiotherapy (to the salivary glands to destroy them totally) or destructive surgery to deal with this problem but if this problem is very severe either and none of the above steps are proving to be helpful then one of these two steps are an option but I would prefer to try to avoid these destructive steps if at all possible.

#### **Summary**

One must not forget the steps that can be put in place before starting her treatment by looking at various steps which could be put in place before reaching for the prescription pad.

Vitally important is to consider the type of saliva production as different medications are used for thick and sticky secretions (viscous) compared to the runny liquid voluminous (non-viscous) saliva problem.

Ultimately though it is not always that one option will be best and sometimes you have to use more than one medication to deal with this problem.

There is a little bit of trial and error in the trying to achieve the best tailor-made treatment for any particular patient. But with quite a few options on the table including now of course Botulinum Toxin Type A (Xeomin) a solution will be achieved.

You can find out more about saliva management at the MND Association website:

www.mndassociation.org/professionals/saliva-problems-in-mnd

**Dr Timothy Harrower** 

**Consultant Neurologist** 

Royal Devon and Exeter Foundation Trust Hospital President of the Exeter and East Devon branch

#### FITNESS, FRIENDSHIP AND FUNDRAISING!

Tri-Hards Ball at Ocean, Exmouth Saturday 26th October 2019

Fitness and friendship have been key ingredients behind the success of 'Tri-Hards' who are Exmouth's largest community sport and fitness group and on 26th October they added fundraising to their repertoire as they hosted the second Tri-Hards Ball.

Two of the group's members, Lisa Findel-Hawkins and Jo Venus, were old school friends who re-connected through exercise and also, sadly, because both of their dads have been diagnosed with MND. Together with Shelly and Neal Stammers who founded Tri-Hards, they organised the ball at the Ocean club, an amazing venue with some of the best views over the Exmouth seafront.

The ball raised an incredible £6,963 thanks in no small part to the sponsors Grapevine and Bradley's Estate Agents and support of numerous local businesses who donated prizes to the auction and raffle.

Lisa commented "Personally, I was absolutely thrilled to see my dad attend the evening. It really did make it so special to have him there. " Lisa's dad Brian, a former Royal Marine, had this to say about the night: "Meeting so many people determined to raise money and awareness of MND is uplifting and reassuring that they all understand what we who live with MND go through daily. Excellent choice of venue, hilarious auction, raffle and speech by Dr Tim Harrower (Neurologist) explaining how MND can affect you. I was amazed at how welcome me and my Carer (Lyn) were greeted by all, in fact we were among the last to leave. Fabulous evening. Well done Tri-Hards."



Pictured: Brian Mackay and daughter Lisa at the ball. Photo credit: Absolute Choice Photography

#### WHAT'S NEW IN MND RESEARCH?

The world of MND research is constantly developing and more and more treatments are being tested and put forward to clinical trials. Below is an overview of some recent news relating to MND research.

#### MND-SMART new clinical trial launched

MND-Smart is a new generation of clinical trials in which multiple treatments are evaluated simultaneously. The trial is led by a team of researchers based in Edinburgh and will test potential new treatments for MND as well as looking at whether existing treatments for other conditions could have some benefit.

Typical clinical trials focus on a single drug – patients receiving the active drug are compared with those who receive an inactive substance, known as the placebo. MND-SMART will allow more than one treatment to be tested against a shared placebo group so that patients have a higher likelihood of receiving an active treatment. People with MND are invited to register interest in the trial at www.mnd-smart.org.

The first participants will be seen in Edinburgh with other clinics across the UK joining during 2020. The recruiting centres Aberdeen, Birmingham, Cambridge, Dundee, Glasgow, Inverness, Irvine, London, Newcastle, Salford, and Southampton.

#### **TUDCA-ALS** clinical trial now recruiting

A Phase 3 clinical trial assessing the safety and effectiveness of TUDCA, which works by camouflaging a stress chemical that triggers the death of a distressed

or damaged cell and may slow progression of the disease, is now recruiting at seven sites across the UK and Ireland. The trial is open to people who are within 18 months of symptom onset and have no swallowing difficulties. If you think you may be eligible to take part, talk to your neurologist who can refer you to a participating centre if appropriate.

www.mndassociation.org/tudca-clinical-trial

#### **International Symposium highlights**

After the recent 30th International Symposium on ALS/MND held in Perth, Australia, where over 900 international research and clinical MND specialist exchanged their findings and knowledge, the MND Association's Research Development Team brings you updates on a variety of topics you might be interested in. Find out more at www.symposium.mndassociation. org/periodic-table

#### **Interested in MND Research?**

If you would like to keep on top of MND research and find out what is happening around the world as well as get invited to new research studies, you can sign up to receive monthly newsletters straight into your inbox or emails to alert you of new research studies (which might not always be clinical trials).

#### Subscribe to the newsletter here:

www.mndassociation.org/mnd-research-newsletter

Subscribe to receive updates on research studies: www.mndassociation.org/mnd-research-list

#### **IMPORTANT NOTICE ABOUT CORONAVIRUS**

We had already discussed this at Committee level and now have received (from MNDA Head Office) direction:

A number of branches and groups have already suspended their get togethers, meetings and support groups to reduce the risk of spreading the virus to people with MND or those in contact with them. Our teams have discussed the ongoing situation with neurology consultants and MND specialists in our care networks and, on their advice, we are recommending that all branch and group meetings where people living with MND and their carers are present taking place before the end of April are suspended. Of course, we will continue to monitor and review the situation and update you if advice changes.

Our advice is also that AVs and other support volunteers should where possible try to avoid face-to-face meetings with people affected by MND for the time being to minimise the risk to those most vulnerable to this virus.

We realise that branch and group get togethers and AV visits are a valuable source of information, social

interaction and support. Do please consider alternative ways of keeping in touch with each other, perhaps by phone calls, emails, Facetime, Skype, social media etc as we want our community to stay connected and in touch.

If you need further support our helpline MND Connect – 0808 802 6262 - is available Monday to Friday between 9am and 5pm and then 7pm to 10.30pm.

Additionally, our AGM will be postponed and under review. Our President Dr Timothy Harrower will present on treatments and new research during our annual Awareness/ AGM as soon as we are able to accommodate members without compromise of risk by meeting under current conditions. Please bear with us. We have a newsletter to update members out online soon.

Accordingly, and for the time being (reviewed towards the end of next month) we will not be having any face to face meetings at the Mardon Center. I know you will understand why and I also know you may feel as frustrated as us - but we cannot afford to take avoidable risks with everyone's welfare.

### THE BENEFITS OF HAVING AN ASSOCIATION VISITOR

Written by Sharon Darton, who is living with MND

Personal contact with someone that understands how you are feeling having been diagnosed with MND - which is often not the diagnosis expected as in my case — is really important. My AV always says on leaving that she is there for me at any time for help and advice: "just ring if you need me". This is a constant reminder that you always have someone there for you. The AV gives someone with MND the opportunity to talk about anything to an independent person.

AVs are also available to carers and family members, as they recognise that this is a trying and life changing time for everyone. The AV can also advise on aids to keep you as independent as possible as the disease progresses, which in turn encourages the improvement of an individual's quality of life.

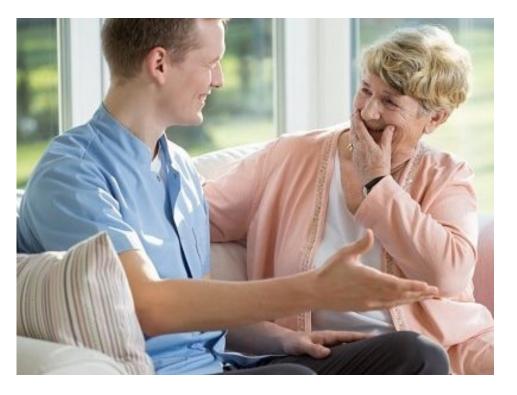
Staying positive and looking at what you CAN do instead of all the things you can't is difficult enough, but the AV gives the support and reassurance for those with MND to keep engaging in what they enjoy as much as possible.

Importantly, the AV has knowledge of the different medical departments to contact as the condition progresses, so is the first port of call for any adjustments required. Friendship between the patient and the AV enables the patient to take interest in their AV's life as they do in the patients, which makes it easy to talk

to them. Regular visits to those with MND who are unable to go out provides the knowledge that they will see someone regularly which is highly beneficial, as social contact is imperative to maintaining good mental wellbeing.

My experience is that your AV is there as your lifeline. They keep you positive and understand when and why you get down or frustrated.

If you think you could be an AV and support families affected by MND in the Devon area, please contact Jo Campbell at jo.campbell@mndassociation.org.



#### **EVENTS**

We have plans for a number of events to be held by the Exeter and East Devon branch in 2020, including the branch AGM and Walk to D'Feet in the Haldon Forest, which is traditionally held around March. Unfortunately, due to the unforeseen circumstances of a national lockdown, we had to cancel all foreseeable events and postpone them until further notice.

Please make sure to follow our Facebook page (www.facebook.com/MNDExeterEastDevon) and keep an eye out for an invitation to the AGM in your post or in the next issue of the newsletter.

#### **MASSIVE THANKS TO ALL SUPPORTERS**

The MND Association Exeter and East Devon branch wouldn't be able to support people living with MND and their families, fund research and campaign without the kind help of everyone who donate their time and money in 2018 and 2019. We would like to send a massive thank you to:

The Exmouth Tri Hards charity, The Grapevine Charity, MCC Promotions Ltd, Topsham Bowling Club, everyone taking part in the Walk to D'Feet, Honiton Show and Lustleigh Show, Mr K Board, Otter Vale Rotary Club, Mrs C Wilson-Pepper, Mr & Mrs D Bastin, Trace & Di from the Otterton Mill, Amy Holland, Margaret Woodley, Bradley's Estate Agents, Rachel Amos (Bandarroch Book Club), Waitrose supermarket in Sidmouth (and everyone who donated through there), Box: House of Marbles (Bovey Tracy), in memory of June Jones, Inchbald School of Design Ltd., Mrs P Portman, Mr N Farrant & Ms M Ellett, Miss J Beauchamp, The Anchor Inn in Sidmouth, Steve and Abi Greenslade (Great West Run 2018), Stephen W & B Rundle, Ms Barbara Farrell, King's Garden Centre in Exmouth, Dawlish Chemists, House of Marbles at Powderham Castle, Ms E Trulock, Exminster Chemists, Mr and Mrs Beecroft, North Curry Community Coffee Shop Ltd, Dawlish Warren Chemists, and everyone else who attended any of our stalls or events in the past couple of years!

### AMAZON SMILE - SUPPORT THE ASSOCIATION WHILE SHOPPING ONLINE

If you are a user of the online shopping platform Amazon, why not make your next shopping experience more rewarding and donate 0.5% of anything you will buy to the MND Association, without an extra cost to you!

Shop and support the MND Association today:

- 1) Sign up for AmazonSmile via smile.amazon.co.uk
- **2)** Search for the 'Motor Neurone Disease Association' via the charity lookup
- 3) Select us as your AmazonSmile charity of choice
- **4)** Look out for products which are marked as "AmazonSmile eligible"
- 5) Enjoy your shopping

#### **RAISING AWARENESS AT THE UNIVERSITY**

Written by Joanna Knott

We recently had the opportunity to have a stand at an event for medical students at Exeter University, to promote motor neuron disease, by informing students and welcoming any that may want to volunteer or support the local Branch. This is the second year that the University have given us this opportunity (which is quite a privilege as ours was the only Health Charity stand present), and the previous year realised the valuable support of Peter Henley, one of the students and our branch volunteer.

The University was extremely supportive and hospitable, enabling us to partake of the lunchtime refreshments. We thank all those involved who enabled us to promote motor neuron disease and thus raise awareness.

If you or anyone you know would like to become a volunteer at our branch and help us with planning and running events, producing a newsletter or becoming an Association Visitor, please contact us.

#### THANK YOU TO ALL BRANCH VOLUNTEERS

This branch couldn't be working without the help of a number of our local volunteers, who consist of a variety of people affected by MND, students of medical sciences, past MND Association employees and other motivated and hard-working people. We are here to support every person affected by MND in the Exeter and East Devon area and we look forward to see you at one of our upcoming events.

#### **CONTACT INFORMATION**

For any branch-related enquires, including support for people with MND, please contact us at **01395 225 227** or email us at **support@mndexetereastdevon.org**.

For more general information, please contact the MND Association national helpline at **0808 802 6262** or at **mndconnect@mndassociation.org**.

You can also find a lot of useful information on www.mndassociation.org.