“I wanted to try my best for all those people who have MND”
Techcess works with clients and therapists to supply and support the most appropriate talking technology.

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As we look towards our 40th anniversary in 2019, I find myself reflecting on how much our Association has grown. The pace and momentum of MND research is greater than ever and I am proud our Association is firmly at the forefront of this work. Someone who has relentlessly pushed forward MND research is our Director of Research Development, Dr Brian Dickie, who marks 20 years at the Association this year. Reading Brian’s article on page 11, as he looks back on his first day at the Association, really shows how far we have come.

A big development for people living with MND, was the long-awaited publication of the NICE guideline on MND, following four years of campaigning. Now we have secured the guideline, we turn our attention to ensuring it is correctly implemented across England, Wales and Northern Ireland. Our Transforming MND Care Audit Tool on page 27 will help health and social care professionals to monitor the care they provide and help us to take action where services fall short of the NICE quality standard.

People living with MND do not have the luxury of time, so getting access to the right support in a timely way is essential. With a condition as relentless and progressive as MND, it can be hard to know exactly what support is available. With this in mind we have created a diagram to show all the ways we can help and you will find this on page 20 and 21. It is heartening to see the many ways we can support people affected by MND and their families and I hope our diagram encourages more people to get in touch.

Nearly forty years ago a group of people, driven by their own devastating experiences of MND, came together to form our charity. Despite the huge growth of the Association, I am proud we remain true to our original aims of putting people with MND at the heart of everything we do.

Thank you for all you do to support us.

Sally Light
Chief Executive
Royal Patron visit to celebrate MND First Contact Group

In January, HRH The Princess Royal visited Butterwick Hospice, Stockton-on-Tees to celebrate the work of the MND First Contact Group. Held every Friday at the hospice, the group provides people living with MND from across the region access to expert advice, peer support and complementary therapies.

TED explains data protection

There are changes to data protection legislation on the horizon with the Data Protection Act set to be replaced by the General Data Protection Regulations in May 2018. On the face of it this is a pretty dry topic, but it is important that Association staff and volunteers are aware of the changes, particularly in light of large fines that have been handed down to charities due to data protection breaches.

To bring the subject to life, we teamed up with the puppeteers behind TED, who have previously portrayed life with MND on stage. We filmed a series of videos for staff and volunteers, each one covering an aspect of the new regulation and we will be releasing the videos over the coming months to our branch and group network.

Our thanks go to Smoking Apples and Dogfish Theatre for their time and expertise in bringing TED and the topic to life.

20th MND Care Centre launches in June

We are committed to ensuring that all people with MND have access to one of our specialist MND Care Centres, or similar co-ordinated support, as close to their home as possible. Following an in-depth analysis of local provision across the country, we have opened our 20th MND Care Centre Network in Sussex and will be holding a special launch early in June. Work on the expansion of our MND Care Centre Network continues with our 21st MND Care Centre due to be opened later this year in Norfolk.

Jeremy Vine becomes Patron

We are thrilled to announce presenter, author and broadcaster Jeremy Vine as our newest Patron. Jeremy will support our national profile, fundraising and campaigning work, having spent the last two years as Patron of the West London and Middlesex Branch - a role he will continue alongside his new position.

Jeremy said: “The MND Association does brilliant work for people who have been struck down by one of the most debilitating illnesses ever known. I am absolutely delighted – and incredibly humbled - to come on board as the charity’s Patron. I have met so many remarkable people living with MND since I first connected with the Association, and I look forward to doing what I can to help in the future, both on a national and local level.”
Credit Suisse aims to raise £620,000

Credit Suisse has announced the MND Association as its UK Charity of the Year partner for 2017. The bank aims to raise £620,000, to fund three key programmes for people with MND.

Part of the money will be invested in our MND Care Centre Network to enable more people with MND to have access to a specialist centre. It will also fund technology to enable people with MND to record their own voice for use in communication equipment, instead of a pre-recorded synthesised voice. Finally, some of the funds will be invested in Project MinE, to understand the genetic causes of MND.

The fundraising has already begun with lots of enthusiasm with events ranging from Valentine’s Day cupcake sales and the Credit Suisse Choir singing love song requests to employees, to a group of 25 people trekking the Sahara Desert.

Moving tribute to an employee

TURNERS of Soham, one of the largest haulage companies in the UK offered the MND Association the chance to advertise on the back of one of its 40ft lorries. When one of their employees, Andrew Grantham sadly died from MND, his wife Julie asked if they would be willing to let the Association use the space. Turner’s were happy to honour Andrew Grantham in this way, in recognition of his long service over 20 years. Our advert features Liam Dywer and is currently travelling around the UK, raising awareness of MND.

Government drops plans to devolve Attendance Allowance

On 19 January 2017 the Government announced it would be dropping plans to devolve Attendance Allowance – a disability benefit for people aged 65 or over – to local authorities. The Association campaigned against this change with 300 Association supporters emailing their MP, and over 100 people with MND, their carers and families travelling to Westminster to talk to MPs, helping us voice our concern that devolving this benefit would create a postcode lottery.

MND Association Chief Executive, Sally Light, said: “Attendance Allowance is a vital benefit for many older people with MND. It enables them to afford basics like clothing and transport that enable them to enjoy as good a quality of life as possible as they battle this progressive and terminal illness. We are pleased that people diagnosed with MND in the future will have access to this important benefit.”

Thank you to everyone who took part in this campaign and helped make the Government listen to our concerns and abandon its plans to devolve Attendance Allowance.

Award winning broadcaster dies of MND

WARD-winning broadcaster Stephen Rhodes, best known for presenting This Morning, The Politics Show, the voice of Family Fortunes and presenter on BBC 3 Counties Radio, has died from MND, aged 66.

Stephen did much to raise awareness of MND both in the media and by speaking at events. As Campaigns Contact for the Luton and South Beds Branch, he was highly instrumental in persuading Bedfordshire Clinical Commissioning Group to joint-fund with the MND Association, a rare neurological conditions nurse specialist.

Dr Jane Hawking, Penny Mordaunt Minister for Disabled People, Work and Health and Sally Light, CEO MND Association
MY partner, Ken, was diagnosed with MND in 2001. From diagnosis to death it took just eight months – it was as brutal and scary as it was rapid. We could never keep up with the relentless progression of the disease. NHS services certainly couldn’t. Without the intervention of the MND Association, and the amazing care from the Regional Care Development Adviser, we would never have received the help we needed at the right time. Even then it was still stressful. During a hospital stay after a fall, one occupational therapist said that Ken couldn’t be discharged until he had learned to walk again. That was indicative of some professionals awareness of MND. All these years later I am still dealing with what happened.

As Chair of the Association, I am involved in the strategic direction of the charity. And, along with the other trustees we ensure it is being properly managed and funds raised are being spent correctly. In the last edition of Thumb Print I introduced our new five-year strategy. I am pleased to say that the development of the strategy was a collaborative process, with you, our members, playing a large part.

I know many of us first get involved in volunteering after experiencing the horror of MND. For me though, I didn’t initially get involved to ‘give something back’. The reason I became involved was for my own survival. I had a horrendous personal experience and I needed to do something as a result.

I wanted to be part of the fight against MND. I wanted to be part of the process making decisions that would have a positive impact. When I first contacted my local branch I saw the dedication and single-minded determination to improve the lives of people with the disease locally. As Chair, I have since visited many other branches and groups. Each one is different but one thing is the same – the absolute dedication and commitment to supporting people with MND.

With the publication of our strategy there is one message that is very important to me personally to get across. My own personal experience has made me very focused on what we are doing today to support people. Yes, the strategy is a long-term plan but we remain focused on how we are supporting people now. We know how fast this disease can progress. We know how horrendous MND can be. We know people need help now. Our strategy outlines how we will continue to be part of this fight against MND, ensure our Association is secure for the future but also maintain the commitment to helping everyone get what they need as soon as possible.

Could you be a trustee?
Nominations for trustee vacancies are now open. If you are interested in becoming a trustee or would like to nominate someone go to www.mndassociation.org/trustees2017. The closing date is Friday 5 May 2017 and candidates will be informed of the result prior to the AGM on Saturday 8 July 2017.
Putting people with MND at the heart of everything we do

SOMETHING that unites all of us within the MND family is our vision of a world free from MND. We believe now more than ever, that achieving it is possible. The increasing pace of research discoveries mean our understanding of MND is growing all the time, making this the perfect moment to chart the next stage of our journey.

While we work towards our vision we will do everything we can to fight MND and ensure people affected get what they need, when they need it. The challenges are many – constrained public spending, ageing population, increased demands on carers – but so are the opportunities (MND research, the NICE guideline on MND, innovations in care). Our five-year strategy, with its six goals, puts us in a strong position to reduce the impact of those challenges and, relentlessly exploit the opportunities.

It describes how we will maintain our commitment to ensuring people affected by MND receive the care and support they need, when they need it, while championing their right to access the very best care. It also shows how we will continue to build on our international reputation for funding and promoting research.

Our strategy was not developed in isolation. It was guided by our vision and mission, created in partnership with people affected by MND, and written alongside a thorough assessment of what is happening in the wider environment.

Our ability to support people with MND will continue to depend on the extraordinary generosity of you, our members and supporters. Thank you for helping us fight this devastating disease.

To deliver our strategy’s goals we will need to raise around £100 million over the next five years.

Our six goals for the next five years

GOAL 1
ADVANCING RESEARCH
We will be a leading international contributor, in identifying the causes of MND and understanding how it progresses. We will support the research community in turning this new knowledge into potential treatments and ultimately a cure.

GOAL 2
ENSURING QUALITY HEALTH AND CARE
We will do all we can to ensure people with MND, their carers and families can access the care, support and information they need, when and where they need it, reflecting their diverse needs.

GOAL 3
STRENGTHENING PROFESSIONALS’ ABILITY TO TREAT AND CARE FOR PEOPLE AFFECTED BY MND
We will better understand the disease and clinical progression of MND. We will facilitate the sharing of knowledge, data and resources to improve outcomes relating to people’s diagnosis, prognosis and treatment.

GOAL 4
WORKING TOGETHER
We will achieve more for people with MND, their carers and families by working in partnership and collaboration with others, and by being a credible and effective operator in the external environment.

GOAL 5
RAISING AWARENESS
We will increase awareness and understanding of MND and raise the profile of the work of the Association to influence decision-makers and reduce the social isolation so often experienced by people with MND.

GOAL 6
THE DIFFERENCE WE MAKE
We will continue to affirm our place as the leading authority on MND by growing the MND community and continually improving how we run our organisation.

Our strategy will be monitored to ensure we are making as much difference as possible. We will also find ever more ways to listen to people with MND, their carers and families, and, by doing so, keep them at the heart of everything we do.
JASON Liversidge from East Riding was diagnosed with MND in August 2013 at 37. Prior to his diagnosis Jason enjoyed an active lifestyle riding motorbikes, shooting, skiing and spending time with his wife and young family.

Within 18 months of his diagnosis Jason’s speech was starting to deteriorate. One day Jason’s wife Elizabeth saw a tweet about a pilot voice banking research project at the Euan McDonald Centre, Edinburgh. The project was part-funded by the MND Association and seeks to create a personalised computer generated voice by mixing a person’s speech with other voices with the same regional accent. Securing a place on the pilot project, the family then appealed for people in Yorkshire to donate their voices. Following the appeal, five firemen stepped in to give Jason back the Yorkshire accent he always had. After speaking about the pilot project on BBC Breakfast, the family found themselves at the centre of a huge media story.

“The Speak Unique research project is a brilliant example of a patient inspired initiative. It exploits cutting edge technologies to solve a major problem for people with MND.”

Jason’s wife Elizabeth speaks to Thumb Print about life with MND: “Hearing the confirmation that Jason had MND was traumatic. It affected us both differently. I cried for three days while Jason was initially in denial. We had two very young children and I was on maternity leave.

“We muddled through and got on with life as best we could. I went into practical mode and looked up everything that could possibly help. Equipment, services and adaptations can take a long time to put in place. Perhaps because of my job as a social worker, I am a good advocate for Jason, willing to fight for his rights and make sure he get everything he needs. You have to push for things, you have to do your research and be prepared.

“Jason’s speech had been deteriorating steadily. We looked into voice banking but sadly his speech was too poor. From our experience we would recommend that people look into voice banking as soon as possible after diagnosis. After contacting the Euan McDonald Centre we were very lucky Jason was accepted onto the pilot. Following our appeal for people with Yorkshire accents to bank their voice we ended up with 21 voice bankers who all travelled up to Edinburgh at their own expense. Five of these were from our local fire station in Bridlington, where Jason was born. After banking their voices the firemen invited us to the Bridlington fire station. We had a fantastic day out with our little girls and made some wonderful memories.

“The media interest in the project and in Jason was huge. However we felt it was important to do the interviews and raise awareness of MND. So many people from all over the world have got in touch, including many people with MND and carers. Jason is committed to continue to raise awareness, and, to share his own experiences of MND to hopefully help others.

“A key part to our life with MND is that we are both determined to make the most of our time together. Jason especially has a real sense of determination to keep challenging himself. Last year this challenge came in the form of him completing the longest and fastest zip wire in Europe despite being severely disabled. Yes, MND is devastating but it does not define us, and, with a little help from our friends – including the firemen – we continue to focus on what matters most.”

Prof Siddharthan Chandran, Director at the Euan McDonald Centre said: “The Speak Unique research project is a brilliant example of a patient inspired initiative. It exploits cutting edge technologies to solve a major problem for people with MND.”
example of a patient inspired initiative. It exploits cutting edge technologies to solve a major problem for people with MND, who experience slurring, disturbed or even loss of speech. Today people are reliant on using ‘generic and impersonal’ synthetic voices to replace their own when their voice is already affected.

“Our study, kick started and led by the Euan MacDonald Centre, uses state of the art methods to build personalised voices from a donor bank in a rapid and simple manner that requires around half an hour of speech recording. It works by blending recordings of a person’s voice with donor voices that are matched for gender, age and regional accent. This technology is currently being piloted and trialled in NHS clinics in Scotland with the anticipation that by the end of the year we will begin the next phase of research - testing beyond Scotland.”

Karen Pearce, Director of Care (South)

How to bank your voice

To bank your voice you need to record between 600 to 3,500 phrases. In total, this will take a minimum of six - eight hours. The synthetic voice can then be stored on a computer for use in the future, when it is required.

To do voice banking you need a computer and a USB connected headset microphone, which are available for around £30 on line (for example, the Sennheiser PC8). You will also need somewhere quiet to record. The MND Association has a small stock of headset microphones available to loan, if required.

There are currently four voice banking services available. In all cases you need to complete a small set of screening sentences before you can proceed with the full recording.

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*A small charge will be introduced in 2017 to download the completed voice to your device
**To download the completed voice on to your own device is approximately £2,000

For people living with MND: 7C – Speech and Communication Support information sheet is available from MND Connect or by visiting www.mndassociation.org/publications
For queries about voice banking or communication aids contact: 0800 802 6262 communicationaids@mndassociation.org
OUR DNA bank is a vital resource for MND researchers. For 10 years we collected blood samples and personal information from people living with MND, their partners and family members. Samples collected years ago are still being used by researchers, leading to new knowledge about the causes of MND.

When we began collecting the samples, there was no way of knowing how rapidly technologies would progress. However, as new knowledge and technologies have emerged, our DNA bank has never been more important. Dr Jean Waters who is living with Progressive Muscular Atrophy (a slower progressing form of MND) was one of the first people to provide a blood sample in 2007. Jean said: "When you are diagnosed, you are suddenly confronted with a disease that has no treatment or a cure, only hope for what research will uncover in the future. Providing a sample felt like a very positive, proactive thing to do."

“It is incredibly heartening to think that by providing that little bit of blood, it has helped with the advancements that we are seeing today.”

Once Jean’s blood was collected, it was divided in two. One half went to a ‘Hub’ centre where a pure DNA sample was extracted. The second half was used as an ‘insurance’ sample in case the supply of DNA ran out. To make sure Jean’s blood cells could be used in the future, they were specially treated so that they would grow forever, creating what is known as a ‘cell line’. Jean’s pure DNA sample was then used for whole genome sequencing. Whole genome sequencing analyses every letter of our DNA – as that is approximately 3 billion letters, it generates a huge amount of information.

This technique might tell us about the genetic contribution to MND in those that don’t have a family history – the so-called ‘susceptibility’ genes. As these effects are likely to be very subtle, it is important to have as many samples as possible to be able to spot these susceptibility genes.

“It is incredibly heartening to think that by providing that little bit of blood, it has helped with the advancements that we are seeing today.”

The Project MinE initiative aims to collect and analyse as many DNA samples as possible from people with MND. MND genetic researchers from around the world are pooling their expertise to interpret the results of the genetic analysis. We have committed to sending approximately 2,000 samples to Project MinE and we are already 75% of the way there.

One way a blood sample can be used to understand what is happening in people with MND is by turning it into a motor
neurone. In the last five years, a new way to grow human motor neurones has been developed. This technique reprogrammes human cells into motor neurones by creating ‘induced pluripotent stem cells’ (iPSCs) as a step in the middle. The reprogramming can start from either blood cells or skin cells. Blood cells from the DNA bank are being used for these studies.

We are currently funding Professor Chris Shaw at King’s College London, to generate iPSCs. Once Professor Shaw and his colleagues have created a good range of iPSCs from different people with MND, these will help researchers in understanding the causes of MND.

**Research Director, Dr Brian Dickie marks 20 years at the Association**

Our Director of Research Development, Dr Brian Dickie, marks 20 years at the MND Association and looks back on his time at the Association.

I will never forget my first day. I walked in and the staff were using computers with tiny six inch green screens. Our research team was just one and a half people (including me) and we were funding three research projects worth around £100,000. Now, our research grants number more than 80 and is topping £14.6million.

The advance of the Internet has helped encourage collaboration and the sharing of information and new findings across continents. Researchers cannot afford to operate in silos and this is particularly true for rare diseases. The impact of international collaboration has been particularly successful in the search for genetic causes of MND, giving rise to initiatives such as Project MinE. While cyberspace is a fantastic tool and facilitator, there is also much to be said for face to face contact outside of the laboratory. What I call coffee queue collaboration remains one of the key reasons the world’s best researchers across so many fields attend our annual International Symposium.

The Association still has its roots in the branch system that evolved soon after the foundation of the charity in 1979. Despite our growing scale and influence as a charity and a research funder, I like to think we haven’t lost our sense of community and people often refer to our MND family. It’s always humbling and inspiring to visit our branches and groups and see the amazing support that we provide to families affected by this devastating disease.

We have come a long way in the past 20 years in our understanding of MND. The challenge now is to turn that understanding into effective treatments. This is a challenge I am increasingly optimistic we can meet!

**Making the link between genetic and environmental factors**

We think the reason most people get MND is due to a combination of lifestyle, environment and genetic factors. To help understand the environmental and lifestyle factors we asked people who had provided a DNA sample to complete a questionnaire covering many things, ranging from the houses they’d lived in, smoking history, jobs, hobbies to their medical history.

Comparing the answers from people with MND with healthy controls will give us clues regarding what factors may contribute to why someone develops MND. This way, researchers will be able to make links between genetic and environmental causes of MND. We have shared this data with Professor Ammar Al-Chalabi at King’s College London to help understand why people develop MND.
We turned our dream into reality

Sue Thompson’s brother, Steve died from MND at the age of just 49. Some years later when Sue was made redundant, she decided to turn it into an opportunity to keep Steve’s memory alive.

“My brother Steve, had MND for 18 months. After he was diagnosed, we desperately searched the internet for a cure and thought we had found one when we read about stem cell treatment in China. We knew it was unproven, but felt it was worth a try. It didn’t work and we lost Steve in October 2006. It was heart-breaking to watch my brother, a first-class builder who had built his own home, deteriorate so quickly.

“I was the manager of the Sue Ryder shop in Romiley, Stockport, when I was told the shop was closing, making me redundant. After the initial shock, I started to develop a dream that wouldn’t go away. I wanted to turn this into an opportunity to raise money to fight MND. Armed with my £4,000 redundancy money, I approached the landlord who agreed to rent the shop to me. I started to advertise on social media asking for donations of clothes, shoes, bric-a-brac, basically anything we could sell to raise money to help in the fight against MND. We were inundated!

“We opened the shop Over the Rainbow on 11 August 2014. To make our purpose known, I poured my heart out, writing on a massive white board about my lovely brother and how I wanted to keep his memory alive. I put it in the window together with photographs of Steve. It worked. Customers came through our doors, not only to buy, but with huge bags full of things for us to sell. Each time I made a donation to the Association, I put a massive cheque in the window, so people could see how much we had given away.

“Since opening Over the Rainbow we have not only raised money to help people with MND, but, just as importantly, we have raised public awareness of this horrible disease.”

“At first the shop was called Over the Rainbow – Fundraising with Sue and Volunteers. After the shop had been opened for five months, the Manchester Branch of the Association got in touch. I was invited to the meetings and I am now on the committee. When we raised £10,000, we had the additional sign for
the MND Association’ added to the front of the shop.

“Over £19,000 has been given to the MND Association and another £3,000 has been spent on equipment for local people with MND. We have also managed to fund a number of special treats for people with MND living locally, which has given me great joy. The shop has become a planning centre for fundraising activities with many sponsored events, including the Ice Bucket Challenge and a Fun Day.

“Since opening Over the Rainbow we have not only raised money to help people with MND, but, just as importantly, we have raised public awareness of this horrible disease. Our venture has become a huge success. I see this as Steve's legacy, because if I hadn't lost Steve, the shop would not exist.

“From having a dream, we have turned it into reality. It’s really hard work but very worthwhile. It is so satisfying to know you are helping. Of course, I would not be able to do all of this without my wonderful team of volunteers – they are my extended family. Over the Rainbow raises awareness of MND every day, and that’s what my dream started with. I have a huge MND family who come from near and far with donations. Our shop is filled to the brim with stock, but also with love.

“Over the Rainbow opened to keep the memory of Steve alive and, even though I still have sleepless nights, it worked. For Steve, my brother, I love you more.”

We need you

As a result of Association Visitor (AV) support:
92% of people living with MND feel more supported
90% of people living with MND feel less isolated

Our AVs make a huge difference, but we need more. Join our vital team today and give more people with MND the chance to access this vital support.

Email volunteering@mndassociation.org or telephone 0345 6044 150

Why don’t we run shops to raise money and awareness?

SUE’S experience of MND is the driving force behind the shop. What she has done, alongside her wonderful volunteers, is absolutely amazing and a huge tribute to their hard work and dedication. However, what has been achieved is very unique to Sue. The MND Association has no plans to invest in a national network of charity shops which are extremely expensive and time consuming to run.

Our existing fundraising activities currently generate £3.60 for every pound we spend and we will continue to invest in fundraising that will help us to raise as much money as possible for people with MND. We do have an online shop where people can buy MND Association-branded goods, without the same overheads as a physical shop.

www.shop.mndassociation.org

SHOP volunteers Olivia and Leanne

Why don’t we run shops to raise money and awareness?

INNOVATIVE SOLUTIONS CUSTOMISED FOR UPFRONT WHEELCHAIR PASSENGERS & DRIVERS

Sirus build the highest quality conversions all backed up by our industry leading 3 year warranty. We offer affordable finance packages and Approved Used cars to suit all budgets.

Ask us about our new and exclusive Self Lifting Ramp System.

Visit our website to build your own Sirus car
www.sirusautomotive.co.uk

Call 0121 505 7777 to book a no obligation home demonstration

www.mndassociation.org 13
Together we are STRONG against MND

Volunteers founded our Association back in 1979. Today, they remain the driving force, with over 7,000 people volunteering their time to support people living with MND, their families and carers.

To help us deliver our ambitious plans to support people with MND over the next five years, we have launched a major volunteer recruitment campaign, STRONG. The more volunteers we have, the more we can achieve for people with MND. Through STRONG we aim to attract new volunteers, who may not have a personal connection to the disease, but who will be motivated to join our cause.

Our STRONG campaign will provide volunteering opportunities for anyone, regardless of the amount of time they can give, so that they can fit volunteering into their current lifestyle. Regardless of whether they have two hours, two days or two weeks to volunteer we have opportunities for everyone.

Every minute of volunteering helps us strive towards our vision of a world free from MND. You can access the STRONG website by visiting www.strong.mndassociation.org

Our AGM is in July and you are all invited

Work is well underway on making this year’s AGM and Annual Conference the best yet. Taking place on Saturday 8 July at the Radisson Blu Hotel, East Midlands Airport, our keynote speaker Prof Ammar Al-Chalabi, Consultant Neurologist will be answering the question we all want to know – Are we really making progress? Alongside his clinical work as Director of the King’s MND Care and Research Centre, Prof Al-Chalabi is involved in research focused on the nature and causes of MND.

Alongside a number of interactive workshops, there will also be the opportunity to hear more about what the NICE guideline on MND means for people with MND and how we are going to ensure it is implemented throughout England, Wales and Northern Ireland.

The conference is a good way to learn more about MND, our work and progress, as well as find out more about the care and support available. It is the biggest event in our calendar, bringing together members, staff, volunteers and fundraisers from across England, Wales and Northern Ireland. As always, we are offering people living with MND and a carer the opportunity to attend free of charge.

For more information visit www.mndassociation.org/regionalconferences
MND doesn’t care about time, but we do

Time is precious:
**Minutes, Hours, Days or Weeks**

Regardless of how much time you have to give, it makes all the difference.

Help us change lives. Become STRONG Against MND.

---

**2 HOURS**

By donating even just 2 hours, there are numerous things you can do to add value to our campaign.

Promoting us through social media by sharing, liking and tweeting our messages will allow us to reach a wider audience meaning you’re making a difference.

---

**2 DAYS**

Help us raise awareness in your local community, whether it’s planning an event or giving a talk to local groups or schools.

However, we understand speaking isn’t for everyone, share your experience about MND through a blog, whatever you choose, you’re making a difference.

---

**2 WEEKS**

Are you someone who has an endless bucket list and fear no challenge?

Skydiving, running a marathon, even running local events will help us to raise essential funds.

Challenge your peers to get involved with you in what you choose to do, everyone will be making a difference.
Planning for pre…

TIME is precious for everyone, but for families affected by MND every moment is precious. With summer approaching, many of you are now planning your holidays. For people with MND, going on holiday can seem impossible at first; but with the right guidance and some planning holidays can be thoroughly enjoyed as some of our Thumb Print readers share.

**Steve Dimond in Seoul**

Following his diagnosis of MND in August 2016, Steve Dimond decided to book a trip to Seoul, South Korea with his daughter. Steve said: “After I got over the initial shock of being diagnosed I knew I wanted to spend the rest of my time making memories with my family. The only thing holding me back was the worry about how my disease would progress by the time of the holiday. However, my desire to create memories was stronger than my fear so off we went. We used the airport’s disabled service and made sure to plan ahead and pre-arrange restaurants and sights.”

**Arthur Newall, Texas**

Arthur Newall, travelled to Austin, Texas. Arthur said: “Once you get over the flight, America is very wheelchair friendly. I have poor speech but many Americans have difficulty understanding people from the UK so I fit in quite well. Although my phone can ‘speak’ for me I find it easier to let people read what I have typed. People in Texas are very friendly, helpful and patient which was brilliant as I was travelling alone.

“My flight from Austin was delayed because of problems loading my wheelchair (the plane had a very small cargo door). I always travel with an A4 sheet of wheelchair instructions and usually just point at the appropriate bit to explain what should be done. “Holidays have the potential to be stressful but with a bit of organisation, acceptance that delays happen and allowing plenty of time you can reduce the stress and enjoy yourself.”

“I have tried taking a manual chair for flights and hiring a chair at my destination but from experience I have learnt it is always more comfortable to use my own chair. Before going on a flight I would recommend reading your wheelchair manual and having it available for the baggage handlers. “Holidays have the potential to be stressful but with a bit of organisation,
Barry Wilson went on his first cruise after being diagnosed with MND in 2012. He describes his holiday on board the cruise ship, Magellan. “We set sail for our Baltic cruise with destinations in Copenhagen, Warenmunde, Talinn, St Petersburg, Helsinki and Stockholm.

“My wife had booked the tours with me in mind and apart from difficulties walking on the many cobbled streets in most places, we managed to avoid stairs. The highlight for me was St. Petersburg with its stunning palaces and churches covered in gold. I think cruising is the best way to travel for those of us with disabilities.”

A few months after Alison Pickard received her diagnosis she thought about how she would manage future holidays. Alison said: “After a bad experience of being booked on the 4th floor of a B&B we bought a caravan as we knew it was accommodation I could cope with. I have a folding handrail fitted to the external door and a handrail fitted in the shower, which is roomy enough to take my shower stool. We looked at my bucket list of places in Europe and we drew up a map. “We decided to combine our tour of Europe with fundraising for the local hospice and the MND Association. I’d never been to Switzerland, it was a bit chilly when we got there as it was only April but it was still beautiful. Our daughters flew out to Venice to see us too and stayed on the same campsite as us. I’m glad I did it then because I think Venice now would be quite difficult on a scooter. It was a great trip and I think we both got bitten by the caravanning bug. As my needs progress, in time, we will trade in our caravan and get an accessible Autosleeper, which has a roll in wetroom and hoist.”

Top tips for flying

The following tips have been compiled by the MND Association and DisabledHolidays.com. There are many companies specialising in providing accessible holidays. For information and advice please contact MND Connect 0808 802 6262.

- Airport assistance can be pre-booked and arranged free of charge. Someone can help you from your taxi at the airport, at the check-in desk, escorting you to the aircraft and helping you to board.

- If you need prescribed feeds and fluid supplements on the plane, they must have the original label and packaging given by a pharmacy, along with a doctor’s note to ensure that they can be taken through security. However please check with your airline before flying, and all ongoing or internal flights, to see if any security restrictions apply.

- Make sure you get travel insurance. Many insurers cover MND. For more advice contact MND Connect.

- Plan ahead and research restaurants, bars and places you want to visit. You may want to check that your destination isn’t hilly and has good accessibility.

- Carry your wheelchair instructions manual with you and read them before your trip.

- Airlines want to know the weight and dimensions of mobility scooters and electric wheelchairs at the time of booking.

- An ‘airsafe’ plug can be purchased to inhibit powered wheelchairs on flights. This device plugs into the charging socket to immobilise the wheelchair and is compatible with most models. This can prevent costly damage, as security regulations may result in wires being cut or removal of the battery. Search for airsafe wheelchair plug online.
Are you ready for

O UR campaigning activities are bringing real change for people with MND. However, we know that there is so much more we need to do to make sure that our voice is heard. We are concerned about cuts to benefits and reductions in funding for statutory services. Our online campaign network of 2,200 volunteers, alongside our trained campaigners on the ground, is now more important than ever before. Thumb Print has spoken to three very different campaigners about how they got involved. From the active campaigner to the occasional one – we need people to join us and help create positive change for people living with MND, their carers and families.

The trained campaigner

C OLIN Hardy started fundraising after his sister Pauline died from MND in 2013. He has since raised £17,000 and, in 2014, became his local branch’s Campaigns Contact where he received training to help campaign effectively. One of his big achievements was getting his local and county council to adopt the MND Charter.

“As a family we went through a torrid time – the system was broken. I found it ridiculous that it cost more for funding panels to sit and agree whether or not to fund a piece of equipment, than the equipment itself actually cost. The timescales we were being told we would have to wait for a piece of equipment certainly didn’t work for my sister, or indeed anyone with MND.

“This is what motivates me as a campaigner. I do not want others to go through what we did. However, it is no good just taking a problem to an MP or councillor. You have to take a solution. That is why campaigning with the MND Association works so well. They have the solution, the information on what to do and the support. When you have all that you find people respond positively to what you are trying to do.

“I am retired and I wanted to get more involved in campaigning. After hearing about the MND Charter I approached Berwick Town Council to sign it. I have also got Northumberland County Council to adopt the Charter and I am in contact with councils in Durham, Cumbria and Gateshead. People with MND don’t have time to wait and I won’t rest until the whole of the North has adopted it.”

Armchair campaigner

J ONATHAN Price’s mum Jan, was diagnosed with MND in 2009. Jonathan and his family were fundraising for the Association when the South West Wales Group asked if he wanted to get more involved. Jonathan went to his first committee meeting and dipped a toe into the role of a campaigner.
action?

Jonathan said: “MND changed everything for my family. I try and harness the raw emotion I feel about my Mum to help other people with MND.

“I was interested in campaigning but wasn’t entirely sure if it would be for me. I work full time so it is important my volunteering can fit into my free time. I do most of my campaigning from home – all I need is a computer and phone. Everyone from the Association has made it clear that there are no obligations or pressure – just do as much or as little as you can.”

Occasional campaigner

ZABUN Nassar was diagnosed with MND in 2016 at 48. She still works at a local secondary school in London, but following her diagnosis has found accessing support challenging. Determined to get the message out that people with MND need support quickly, Zabun has taken up the role as an occasional campaigner.

Zabun said: “I couldn’t believe it when I was told I had MND. It hit me hard, but I decided that I had to keep positive.

“We need to make politicians and decision makers realise how much help people with MND need. Until recently I lived in a flat that was inaccessible and I wasn’t able to leave for weeks while I was being rehoused. With MND, your needs keep progressing and services need to be able to keep up. People shouldn’t have to make numerous calls, emails and letters to their council to get the support they need.

“We need to make politicians and decision makers realise how much help people with MND need.”

Campaigning for better care

As reported in the last edition of Thumb Print the Continuing Health Care Alliance published a report detailing the failings of NHS Continuing Health Care (CHC) and launched a campaign to improve the CHC system.

Over 500 people shared the report with MPs and nearly 400 Clinical Commissioning Groups (CCGs). The Department of Health is leading a revision of the national framework for CHC and there will be an opportunity to contribute to a formal consultation, which is expected later this year. This will include a review of the recommendations made by the CHC Alliance in its report.

At the same time, NHS England is focusing on making improvements to the CHC system, and is considering new measures to monitor CCG performance.

CHC is a vital source of support for many people, and it is essential that the Government acts on the recommendations of the CHC Alliance to address the problems identified in its report. We will continue to campaign so that everyone entitled to CHC support receives the care they need.

Parliamentary inquiry into access to PIP

The All-Party Parliamentary Group (APPG) on MND has launched an inquiry into access to Personal Independence Payment (PIP) for people with MND.

PIP is a benefit for people aged under 65 to help pay for the extra costs of living with a disability or health condition. The APPG has gathered evidence from people with MND and their families and will be launching the findings at our annual parliamentary reception in June.

We will be using the findings to campaign for better access to PIP and other benefits for people with MND.

Please encourage your MP to attend the parliamentary reception – visit www.mndassociation.org/reception 2017
Whether you’re a person with MND, carer, family member or friend, you can speak to us at the MND Connect Helpline on 0808 802 5454. Available Monday to Friday, 9am to 5pm and 7pm on Thursday.

We help you with:
- Communication aids support
- Equipment loan
- Wheelchair support
- Providing grants
- Welfare benefits advice
- MND Connect Helpline
- Every day living

People affected by MND, Carers, Living with MND.
can help you

INFORMATION AND SUPPORT

26262
MND Association.org
Available daily
8am - 10.30pm

Online care forum

Information guides and leaflets

www.mndassociation.org

Website

21 MND Care
Centres

89 branches and groups providing local support

Remember, friend or volunteer... WE ARE HERE TO HELP
Thanks to you we raised £95,000

Thank you to all our members who entered and sold tickets for our Christmas raffle. You helped raise over £95,000 to support people with MND and their families.

Congratulations to all of our prize winners including Nicholas Beale who won our first prize of £4,000, Mark Tucker who won £500 and John Nelson who won £200. For the full list of winners, please visit www.mndassociation.org/raffle

“It is so important that the Association raises money, not just to support people living with the disease and their carers, but also to fund research and ultimately find the cure we are so desperate to see.”

You have another opportunity to be in with a chance of winning over 70 prizes in our summer raffle. Every ticket sold supports our vital work to improve care for people with MND and fund world-class research. Eddie Thomas, from Swansea who is living with MND, will be appearing on the new tickets and is pictured with one of 50 cuddly orangutans you can win if you enter before the 5 May.

Eddie said: “Please support the MND Association’s summer raffle. It is so important that the Association raises money, not just to support people living with the disease and their carers, but also to fund research and ultimately find the cure we are so desperate to see.”

Visit www.raffleentry.org.uk/mnda to enter online or call our ticket hotline on 0345 6016 936. You can also order books of tickets to sell to friends and family by emailing raffle@mndassociation.org Each ticket costs just £1 and the more that are sold, the bigger difference we can make for people living with MND. The raffle closes Monday 12 June and the lucky winners will be drawn on Monday 19 June. Regulations mean entry is open to all UK residents excluding Northern Ireland, Jersey, Guernsey and the Isle of Man.

Sons help dad over the finish line

KEVIN Boyle, 68, from Northern Ireland led a very active life, completing eight marathons, 14 half marathons and countless 10 and 5k runs, raising a stunning £40,000 for various charities. In January 2016 he was diagnosed with MND. A committed runner Kevin was determined to continue to run as long as he possibly could, raising money for the MND Association.

Speaking about the first time he knew something was wrong Kevin said: “I did the 120km Camino Walk in Spain in September and I felt really fit. But I noticed my voice was a bit husky. Then I began to slur my speech. By the end of November it had got worse so the doctors started more tests on me.”

Despite his deteriorating condition he was determined to take part in the Derry Half Marathon in September 2016. Sons Kevin Jr and Stephen wanted to make sure their dad achieved his wish so each completed a stage and were there at the end alongside members of Kevin’s running club, to help him over the finish line. In January, Kevin sadly died from MND.
Cocktail crawl raises £3,400

YOU don’t need to run a marathon or jump out of a plane to raise money for the Association as three ladies proved with their unique fundraising event, that saw an entire town covered with MND Association blue and orange.

Following their own personal experience of MND, Katy Wooldridge, Clare Farmer and Rebecca Cass decided to organise a cocktail crawl to raise money for the Association.

The Bewdley Cocktail Crawl was organised with military precision. Between them they visited 14 pubs and bars across Bewdley with every venue displaying MND Association banners, balloons and tins. All the bar staff wore our MND Association t-shirts, adding to the orange and blue colours taking over the town.

Each venue was tasked with inventing its own cocktail which would be sold at a discounted price to anyone who had an MND Association wristband. The wristbands were sold leading up to the event for £15 each.

Rebecca Cass said: “We have all had personal experience of MND and lost someone very dear to us. We have been the carers and lived through this devastating disease. But ever determined, we wanted to do something proactive to fight the battle against MND. We were inspired by a desire to help families coping with MND and our love of cocktails.”

The night made £3,400. We are so impressed with Katy, Clare and Rebecca’s efforts that we are developing a pack so that you can organise one in your area. If you would like to get in touch about organising your own cocktail crawl or any other fundraising event please contact: fundraising@mndassociation.org for some help and advice.

Make MND Association part of your special event

KYLIE Flett and Paul Power recently got married in South Africa. Once they got back to Rochdale they threw a party for family and friends. Kylie’s dad Ken died of MND and so Kylie, wanting to find a way of honouring her Dad, included the Thumbs Up badges as part of the day. Since Kylie’s special day we have launched our new favour cards that can be used as part of any special event.

If you have a special occasion coming up why not support the MND Association and buy our new favour cards at shop at www.shop.mndassociation.org.
Children turning personal experience into action

IN previous editions of *Thumb Print* we have reported on the work we are doing to support children and young people affected by MND. Since then, we have been struck by the numbers of children who are raising money and awareness of MND. Many have seen the devastating impact of MND first-hand and want to do something to help. Here we highlight some of their brilliant and inspirational stories.

ARCHIE Croft, 7, didn’t know anything about MND until his mum and dad told him his great grandad, Alan Ward had been diagnosed. Archie talks about his experience of running in the Mini Great South Run, a 1.5k race for young runners aged three years up to eight. Archie said: “When I found out that my Great Grandad had MND I was very sad and when he died I wanted to do something to remember him.

“My Mum and Grandad had done runs to raise money and I thought it looked fun so I took part in the Mini Great South Run. I was very nervous, but felt proud as I was wearing my MND t-shirt. When I was running I heard a lady shout ‘MND’ which made me go even faster. I was really shocked and very happy at how fast I had run with my time of eight minutes and five seconds. When I got my medal I couldn’t believe it. I wanted to try my best for all those people who have MND. I was amazed by how much I raised as I’d put £50 target on my JustGiving page and ended up raising £650. “When it’s dark and I look up at the sky, they say the brightest light you can see is Venus, but I think it might be my Great Grandad’s star.”

Archie Croft
Sophie and friends at their bakeit! event

SOPHIE Craddock’s dad was diagnosed in 2015 when she was only 10. Sophie wanted to do something to help so contacted the Association to register her bakeit! cake sale. With some help from her friends, the cake sale was held at her school. Sophie said: “My Dad has MND and I love baking, so my friends and I thought it would be a good idea to do a bake sale. We held it on an open evening when we knew lots of people would be attending.”

Sophie enjoyed fundraising so much that when she heard about the Christmas Carols on the village green, she thought it would be a great opportunity to hold another bakeit! cake sale to raise more money. “It was hard work co-ordinating everything and I did get a bit stressed. It was a very cold night, but there was a great atmosphere and Mum and our carer brought Dad to see my stall. By the end of the evening we had sold out and had given away a Christmas cake my sister and I made, as the prize for ‘Guess the weight of the cake.’ We raised £550 and the event organiser didn’t charge us for our pitch and decided to donate the money from the other pitch fees to the MND Association too!”

Sadly Sophie’s dad died in January and the family have since created a Tribute Fund in his name which Sophie’s donations have been added to.

JACK Purdy is now 13 and started fundraising in 2015, after his grandad was diagnosed with MND. He has organised lots of events at his school and raised money and awareness of MND. He took part in Silence Speaks with his friend Charlie and held many bakeit! cake sales, alongside his school friends, raising a brilliant £970.

Jack’s school has been very supportive and invited him to give a talk about MND in assembly. The school received an award for their charity work, which Jack had the pleasure of accepting from the Lord Lieutenant.

Jack said: “My Grandad was an amazing person, he would have helped anyone and everyone. When he was diagnosed I didn’t have a clue what MND was but the MND Association sent out an information pack explaining MND. Grandad went downhill very fast towards the end. He inspired me to fundraise because I didn’t want other people suffering like Grandad did. I also wanted to do something because most people have not heard of MND. Now, nearly everyone in my school knows what it is and that is what I wanted to achieve. I will always fundraise for the MND Association.”

GERRY Taylor’s dad Lee has MND. Lee was heavily involved in setting up the York Group and has spoken at events about living with MND. Now Gerry has decided to get involved in raising awareness and is writing a journal for the group’s newsletter.

November 2016
It’s been one year and four months since Dad was diagnosed with MND. It is really hard to get over the fact that my Dad has this horrible disease. This is especially hard as I am adopted and he was supposed to be my forever dad, but this mean disease is in my way.

Sometimes it’s hard because I think about my wedding day and wonder if he will be there to walk me down the aisle. At school it gets in my head and it stops me from being able to concentrate. I find myself daydreaming about Dad (and also my guinea pigs).

The bad things about MND are:
• It makes you feel rubbish.
• It makes your family sad.
• It makes you feel trapped with no options.
• You can’t make it better!

The better things about MND are:
• It makes you spend more time as a family because you do not know how much time you have left together.
• You can raise money for others to give hope for a cure.
• I have met friendly and supportive people from the MND Association.
• You feel more supported; it feels like an extended family!

I try to take a moment to think about what is going on in other people’s lives and not just think about my own. Other people are going through their own hard times; we are lucky to have the MND Association to help. We all just have to keep on raising and donating money for a cure.

Need support for your child?
Our information and services to support children and young people may help. We also have a special area on our website www.mndassociation.org/ypinfo, a Young Connect helpline on 0808 802 6262 or youngconnect@mndassociation.org and you might wish to apply for a young person’s grant.
THROUGHOUT our Awareness Month this June we will be telling inspiring stories of real people living with MND. The Story Behind the Eyes campaign will show the impact of MND using images of peoples eyes.

Posters will be unveiled from 1 June across England, Wales and Northern Ireland on the National Rail network, the London Underground and buses.

"While primarily an awareness campaign, it is also an opportunity to engage more people in becoming potential fundraisers or volunteers for the charity."

We want as many people to get involved as possible and will be inviting the public to participate too. Watch out on our social media channels in the coming weeks. To find out how to get involved visit facebook.com/mndassociation or @mndassoc for our Twitter account.

This year, we have been given the opportunity to use Birmingham's Media Eyes, three large and uniquely shaped digital screens located at the main entrances to New Street Station. We will be using the main screen for Global MND Awareness Day on 21 June to engage with commuters and share social media messages of support.

Previous Awareness Month campaigns include Shortened Stories (pictured above) in 2016; looking at lives cut short by the disease using posters, a video, blog and time lapse art work. In 2015 our Last Summer campaign showed the reality for people living with MND, a year on from the Ice Bucket Challenge. Meanwhile our Voice campaign in 2014 highlighted that more than 80% of people with MND will experience communication difficulties before they die.

Leicester-based agency Big Dog has been appointed to give design and creative support to the 2017 Story Behind the Eyes campaign.

Chris James, Director for External Affairs at the MND Association said: “While primarily an awareness campaign, it is also an opportunity to engage more people in becoming potential fundraisers or volunteers for the charity. Better awareness grows our voice to make our campaigning more effective and we know this activity helps people affected by the disease feel that they are neither alone nor forgotten.”
**Transforming MND Care Audit Tool**

In February 2016, the NICE guideline on MND was launched, paving the way for better care for people with MND, regardless of where they live. To ensure people with MND are receiving the care they should expect from the guideline, the MND Association has developed a resource tool to help health and social care professionals (HSCPs) monitor how well clinical care provision meets the standards set out in the NICE guideline on MND.

Launched on 2 March, the Transforming MND Care audit toolkit consists of two parts – a computer based clinical audit of the care people, with MND are receiving and a complimentary patient experience survey to monitor how well the service they receive is rated.

Once completed, HSCPs receive a report from the MND Association for future planning and improvement.

A group, including people living with MND, carers, MND Association staff, HSCPs and audit specialists worked together to develop the resource. It was piloted by a range of care service providers and has been endorsed by several royal colleges and professional bodies. Clare Davis, MND Nurse Specialist at the Sussex Community NHS Trust said: “This is useful to benchmark where we are against the NICE guideline and identify where we need to improve.”

Please ask any HSCPs you are in contact with if the Transforming MND Care audit tool is being implemented in their clinic. Working in partnership with organisations in this way, we can drive up service provision for everyone with MND.

For more information please visit www.mndassociation.org/transformcare

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**Michael Holden recognised in Queen’s New Year’s Honours List**

Michael Holden, 45, living with MND, from County Down has been recognised for his ‘services to the disabled community in Northern Ireland’ and been named a Member of the Order of the British Empire (MBE) in the Queen’s New Year’s Honours List.

Michael, who lives with his wife Jennifer and two children Georgia and Noah, was diagnosed with MND in December 2010. He overcame the shock of his diagnosis to set up a travel review site for disabled people, trip-ability.com. The user-led website is dedicated to sharing experiences of travel, entertainment and products with the disabled community around the world and also provides employment for the disabled.

Michael said: “I received a letter about the MBE but my wife Jennifer told me about it over the phone when I wasn’t at home and I immediately began to tremble with excitement.

“My greatest achievement to date without a doubt it is my continued battle against MND and surviving each day with renewed energy with the help of my friends and family, and most importantly with God given strength, for which I give thanks daily. When I was first diagnosed with MND, I didn’t want to meet anyone else with the condition but over the years I have met people through the MND Association and I have found it helpful.”

Michael went on to start up the website www.trip-ability.com which is like Trip Advisor but is for people with mobility problems. It’s been such a success they’ve had to redevelop it to deal with the traffic.

“My greatest achievement to date without a doubt it is my continued battle against MND and surviving each day with renewed energy with the help of my friends and family.”

He also qualified as a pilot four years after his diagnosis through training at Aerobility, a specialist flying school for disabled people, and made his specially-adapted plane available at Newtownards airfield so local people with disabilities could have the opportunity to fly.
A good goodbye

Talking about dying and planning ahead may not be easy, but it can help us make the most of life and spare loved ones from making difficult decisions on our behalf. Not having the conversation can often be the reason why people's wishes go ignored or unfulfilled.

Surveys of people living with MND show that the end of life is something they often want to discuss with both their family and healthcare professionals, despite it being a difficult subject.

Jude Sellmeyer's son Jody was diagnosed with MND in July 2014 aged 36. From the moment he received the diagnosis, Jody focused on making the most of every moment he had left. For Jody, that included talking about his death openly and making plans for when it came.

Jude said: "I have always had a brilliant relationship with Jody. He travelled the world and fell in love with Australia. In 2013 a work opportunity came up in Sydney and he went to live his dream. Jody's life, and all of ours, was changed forever when he got a diagnosis of MND. He travelled around his beloved Australia for three months and then returned to the UK to live with me in a small village in Yorkshire."

"Jody was so independent and free-spirited. He was frank and talked about the stuff that people would skirt around. I always thought that was amazing. Even in the months before he died, Jody was still ticking things off his Bucket List including appearing in a double page spread of the Sydney Opera House before his diagnosis of MND."
Debate on assisted dying

ONE aspect of death and dying that is often widely reported in the media is the ongoing debate calling for a change to the law on assisted dying. You may have seen in the media recently Noel Conway, who is living with MND, seeking permission for a Judicial Review. He wants to see a change to the law on assisted dying to allow terminally ill adults who meet strict criteria to make their own decisions about ending their lives.

The MND Association supports all people with MND, their families and carers in England, Wales and Northern Ireland. We are a membership organisation and our members hold a wide range of views on assisted dying.

We take a position of neutrality toward any change in the law. We always work within the law and do not provide encouragement or assistance to people wishing to pursue an assisted death. We provide information and support to help people have these difficult conversations. We also campaign for access to appropriate high-quality palliative and end-of-life care for everyone with MND, regardless of where they live or personal circumstances.

Advance decision to refuse treatment

Also known as an advanced directive or a living will, it is a legal document in which a person can specify their wishes if they are no longer able to make decisions for themselves.

For more information contact MND Connect or download 14A Advance decision to refuse treatment from www.mndassociation.org/mndsheets
When Elena Luty’s dad, David, was eventually diagnosed with MND it marked a devastating and traumatic turning point for the whole family. Wanting to focus on something positive by raising funds to support our work, the family created an MND Association Fightback Fund. A while after David’s death in January 2015, the family, determined to continue to raise money in his memory, decided to move their Fightback Fund into a Tribute Fund. Elena talks about her dad and how fundraising taught them a great deal about how much people cared.

“Looking back over what we have raised and achieved as a family, I feel so proud. We were deeply touched by seeing how friends came together to support us. It has been truly the most horrendous experience, but fundraising has provided us with a focus to help us through the dark days.

“My wonderful Dad was a proud man who worked hard. An electrician, he worked his way up from being an apprentice to Managing Director. Looking back, the first symptoms of MND were in August 2012, when he started to trip. Weeks later, while gardening, he realised he couldn’t lift his arms. A visit to his GP was followed by a visit to hospital. Scans showed he had a bone growth on his spine causing pressure on his nerve. Dad underwent an operation to remove the growth, however weeks later he was deteriorating and increasingly finding everyday tasks difficult. He was admitted to hospital for 12 weeks, and despite being determined to walk out of the doors himself, this sadly wasn’t possible. Finally in June 2013 we received the news we never wanted to hear.

“I arrived home from work, and, along with my brother Ryan, was told that Dad had MND. Straightaway the pain hit me and my whole world changed. I knew immediately what it meant. Ryan was only 16 at the time and so my mum Caroline, had to sit down and explain what would happen to our beloved Dad.

“From that moment on life became extremely difficult. He was rapidly deteriorating and required a laptop to speak, had a feeding tube and needed assistance for pretty much everything. “We threw ourselves into fundraising, set up the Fightback Fund and Team Luty
If we are to achieve our vision of a world free from MND, while also providing the best possible care and support for people affected by this cruel disease, then we must continue to raise the substantial income to meet the costs involved.

We rely on voluntary donations of which legacies are a vital source, accounting for almost a third of our total income over the last decade.

Without legacies, we could not maintain the same high level of investment in research or the breadth and quality of our care and support services.

So we are asking for your help, to ensure we can continue our fight against MND, by leaving a legacy to the MND Association in your Will.

The Fightback Fund was brilliant. It was something to keep working towards and feeling proud that you, alongside some very wonderful people, have raised money to support people with this horrible disease. I never thought we would raise as much money as we have: £17,000 so far. I know my Dad would be proud. It goes to show there is fantastic support out there and opportunities to help, not only your own loved ones, but others too.

“Following Dad’s death in January 2015, just 18 months after he was diagnosed with MND, we decided to move our Fightback Fund to a permanent MND Association Tribute Fund in his memory. Team Luty has now become The David Luty Tribute Fund. The transfer to the Tribute Fund was so simple and smooth. I received all the information just a day after speaking to the MND Association. This was really helpful as it explained in more detail how it would work. I am very grateful for this and I would definitely say that the love and support given by the MND Association made the transition as easy and simple as it could be.

“This year, we look forward to raising even more money in Dad’s name and the time when I look at the balance it will say £20,000!”

To find out more about MND Association Fightback Funds or Tribute Funds, please visit www.mndassociation.org/get-involved/fundraising or call 01604 611864.
INCE April 2015, everyone should be able to access their GP summary medical records online. This can give you greater control when managing MND and may also be useful when facing the challenges of a caring role, which can affect your wellbeing.

Contact your GP practice for advice on how to get access or look at NHS Choices – search for ‘how to access your records’ www.nhs.uk. If you want to access someone else’s health records, you must:

- be acting on their behalf with their consent, or
- have legal authority to make decisions on their behalf (power of attorney), or
- have another legal basis for access.

If you want to view your written medical records, rather than online, you can make an informal request during a consultation. Or phone the surgery or hospital to arrange a time to see your records.

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Bursary for professionals

We have launched an education bursary for health and social care professionals (HSCPs). We are offering a limited number of bursaries, up to £250, to professionals supporting people affected by MND. To apply online visit www.mndassociation.org/bursary

Advanced masterclass

We are collaborating with Professor Sharon Abrahams and Faith Hodgins of the University of Edinburgh to provide an advanced masterclass for (HSCPs) on cognitive change and frontotemporal dementia (FTD) at nine locations across England, Wales and Northern Ireland. The session will include an overview of cognitive change and FTD, and participants will learn how to use the Edinburgh Cognitive and Behavioural ALS Screen (ECAS) and management strategies will also be covered.

To register go to www.mndassociation.org/advancedmasterclasses

How Dane’s invention is helping those with MND

A n inventor from Yorkshire has created a mattress which he says will enable people living with MND to retain their independence for longer. Dane McGee from Leeds is the inventor behind Comfier™, an in-bed positioning system, which helps people with mobility problems retain control over the comfort of their bed using a special mattress made up of ten inflatable tubes.

“I had always felt that I didn’t want to wake my family up when I needed to change position in bed and now I don’t have to. The bed has taken away the anxiety I had about maintaining independence as this horrible disease progresses.”

When used with a profiling bed, the mattress can be operated with a hand held remote control or eye gaze system to allow the individual to maintain control over their sleeping position, without the need for additional assistance.

Dane explained: “In 2009 I stumbled across Sarah’s Story on the MND Association’s website and found out more about MND and how it affected those living with it. I decided there and then that I wanted to do something to help.”

With support from the MND Association’s Yorkshire Branch, Dane was able to speak to people living with MND to see if he could develop something which would be of benefit.

Among the first to use Dane’s invention was Alan Livett (pictured) from Bradford who is living with MND. Alan said: “I had always felt that I didn’t want to wake my family up when I needed to change position in bed and now I don’t have to. The bed has taken away the anxiety I had about maintaining independence as this horrible disease progresses.”

To find out more visit www.mobilitywithdignity.com
Using a grant from the Department of Health we worked with three wheelchair manufacturers to develop a prescription for a Powered Neuro Wheelchair, designed to meet the needs of the majority of people with MND. People with MND and their carers were involved in this development and the new models are now available for wheelchair services to prescribe.

To access the right wheelchair, it is important to request a referral to your local wheelchair service, at an early stage, for a posture and mobility assessment, and also to discuss the Powered Neuro Wheelchair during the assessment process. If the assessment process identifies other add-on features that the statutory service doesn’t fund (for example, attendant controls or a seat riser) the MND Association may be able to help through a support grant at: www.mndassociation.org/financialsupport

For more information you can watch a film on our website www.mndassociation.org/wheelchair or contact Mary Collier, Wheelchair Support Service Co-ordinator, at wheelchairs@mndassociation.org

Take this prescription to your assessment
Supporting carers, the story so far

In 2015 we undertook a carers survey into the experiences and views of carers of people living with MND. The results from the survey showed that caring for people with MND was more time-consuming than for people with other conditions, with over 50% of MND carers spending more than 100 hours a week caring.

We were staggered to find that more than one third of carers (38%) are unaware of their right to a carers assessment and only 33% of carers have had one. All carers have a right to have a carers assessment by their local authority and we encourage people to do so.

Using information from our carers survey, last year we submitted a report to Government telling them what they need to do to improve support for carers of people with MND. As Thumb Print went to press, the Government was due to publish its new Carers Strategy. We hope it will set out new ways of supporting carers and will be repeating the survey in May, alongside our survey for people with MND, The Improving MND Care Survey. The information these surveys provide is vital when planning our care priorities and campaigning activities.

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If you are a person with MND or a carer we urge you to respond to these surveys. Understanding your needs means we are better equipped to meet them, and design our services around what is important to you.

So far £96,000 has been awarded to carers. Applications for grants can be made on our website www.mndassociation.org/financialsupport or via MND Connect on 0808 802 6262.

We updated our carers guide, Caring and MND – support for you. This guide has so far been requested over 1,750 times.

To help build up a local network of support for carers we are in the process of producing guidance for our branches and groups on setting up carers support groups. Two have already been set up in Cleveland and Nottingham and we are looking to develop more across England, Wales and Northern Ireland.

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Prime Minister receives MND Charter

Charles Dowie, who is living with MND, didn’t expect to meet with the Prime Minister Theresa May when he attended the Conservative Councillors Association (CCA) Conference.

Charles said, “That day, as most days, it took no small effort to get out of bed, shower and get dressed. However, I made the effort in order to ask our local government councillors for their help, not just for me and others living with this disease, but also for my carer and all carers of people with MND.

“I asked them to consider the routine daily tasks that they do, like putting on clothes or turning over in bed, and then to imagine not being able to move their arms or legs as you do these tasks. When the Prime Minister came to our stand, we saw it as a perfect opportunity to talk to her about the needs of people living with MND and the great effort and commitment needed from carers to support them. She now has a personal copy of our MND Charter in her hands.”

One of the most powerful ways to raise awareness with politicians and other decision makers to help bring about change, is by sharing real life stories and experiences. Supporters who have joined our Champion The Charter campaign have been sharing their stories with councillors across the country, and as a result nearly 40 councils have adopted the MND Charter. Support our campaign www.mndcharter.org
Jeff fun run for new MND group

Jeff Cutting, his family and friends decided they wanted to do something to help after Jeff was diagnosed with MND last year. A keen runner, Jeff organised a fun run and set himself the challenge of running up Calver Hill in Reeth, North Yorkshire, raising £7,300 for the newly formed Durham and Darlington Group and MND research. Jeff is now helping to organise a Walk to D’feet at Hardwick Hall in Sedgefield. The walk will bring together the Durham and Darlington, Hambleton and Richmondshire and Cleveland Groups on Sunday 16 July and is open to all.

Jeff said: “I would like to thank everyone who participated in the event, I was staggered by the kindness shown to me. I appreciated all the help I received from family and friends and all the wonderful donations.”

Daredevil Chair

Marian Wilson, Chair of the Montgomeryshire Branch undertook two zip wire challenges raising £1,300. The branch also received over £4,000 from Mrs Ann Tudor High Sherriff who had nominated them as one of her chosen charities during her year of office.

Ukulele band and paella lunch raise £500

Members and supporters of the East Surrey Branch attended the branch’s first open meeting of the year and enjoyed a special paella lunch and an afternoon of ukulele entertainment by Anchor Ukulele Band, raising almost £500 for the branch.

Proposing the traditional New Year toast to the Association, branch Chair Simon Edmands gave a brief outline of the branch’s events and activities for the coming year and was delighted to accept cheques for the Association, totalling over £2,500, from two local Masonic lodges.

Bravissimo

Cubley Hall Hotel in Penistone, South Yorkshire, held an Italian evening and raised £6,500 for the South Yorkshire Branch. The hotel wanted to raise money for the Association after two members of staff received a diagnosis of MND. They presented the cheque to branch Chair, Mel White.

Support from the local

The Red Lion Public House in Blue Town, Isle of Sheppey is fundraising for the Mid Kent Branch in support of one of their locals, Nigel Prettyjohns, who is living with MND. They have raised an amazing £3,600 from a number of fundraising events.
We drove all night: Andrew Green, Richard Baines, Louis Baugh and Robin Baines drove from John O’Groats to Land’s End in a 1936 open top Austin 7, in memory of their father, grandfather and friend, David Baines. The epic trip took more than 39 hours, driving at a top speed of 40-45 miles per hour with just one brief stop in Widnes. Robin said: “We had some challenging night driving when the headlights would switch themselves off and on and the wipers stopped working during heavy rain. Our support car, driven by Marian Green, also suffered a broken tow bar and trailer, but it was a great team effort and a fitting tribute to David and his beloved Austin 7.” The team raised nearly £4,000.

A family affair: Amie Godfrey and her family organised a ball and family fun day raising £2,750 for the Norwich and Waveney Branch in memory of her father-in-law Noel Godfrey. Amie said: “We were thrilled to sell over 90 tickets to the ball and we managed to obtain signed football shirts from Michael Owen, Thierry Henry, Eden Hazard, Ruud Gullit and the Norwich City FC squad to auction off on the night.”

A birthday gift at 12,000 feet: Just four days before Lakhvinder Sarai cashed in his 40th birthday present of a tandem skydive, he decided to collect some sponsorship for the MND Association. His uncle Baldev Mavi is living with MND, so he wanted to use the challenge to raise money in his honour. Lakhvinder raised a whopping £900 and couldn’t wait to show his uncle a DVD of his experience.

Shooting hoops: Maya Hanspal, an ALS researcher at Cambridge University organised a basketball tournament in December, raising £560. The event was in support of her mentor, an Australian MND researcher who has a family history of MND. He played basketball for the Illawarra Hawks in New South Wales, making the basketball tournament a particularly fitting fundraiser.

A marathon effort: Gavin Paley (pictured) enjoys a refreshing pint after running the Palma Marathon in October, raising £1,200. October proved to be a busy month of fundraising for the family. Gavin’s dad Malcolm Paley, alongside Bishop Auckland Hospital Social Club, organised a Halloween party and raised £590 for the Durham and Darlington Group. The money was raised in memory of wife and mum, Carol Paley.

For our friends: Ladies Captain Pam Evans with the Felixstowe Ferry Golf Club, Suffolk, organised a number of fundraising events. Pam wanted to raise money in honour of her childhood friend, Rose Halls, and Steff Stirrat, a past Ladies Captain, who both died of MND. Thanks to the generosity of club members they raised a fantastic £2,650.

Thank you...

Share your pictures at www.facebook.com/mndassociation
Remembering John: Hazel Lewis and her niece, Mei Lewis raised over £700 from their coffee morning held in memory of Hazel’s husband John Lewis. Since John’s death in 2015 Hazel and Mei have raised over £4,500 for John’s tribute fund.

Last lap joy: Jonathan Coleman, whose mum, is living with MND, undertook a marathon, raising £1,550. Jonathan said: “The marathon was really tough. Around the 18th mile my legs started to shutdown and all motivation had gone. Luckily I had prepared for this and reduced my pace. The last lap felt like joy and while I couldn’t sprint to the finish, I kept my pace, motivated by all the people who had supported me.”

Thank you: Paul Dix took part in the Conwy half marathon in memory of Lynda Hodgin who died of MND in June 2016. Paul who was fast approaching 69 at the time, completed the half marathon in 2 hours 27 minutes 3 seconds, raising nearly £700.

A colleague’s tribute: Staff from Tesco New Store and Refresh Team walked all the bridges of London in memory of their good friend and colleague Paul Pemberton who died of MND in 2016, raising £3,000. Since Paul’s diagnosis in 2014 the team has raised over £11,000 to support the MND Association.

Walking for Dad: Rachel and Duncan James walked 14 miles from Eastbourne Pier to Alfriston to raise money in memory of Rachel’s dad John Hadlow who died in February 2015, raising over £1,000. Rachel said: “It is heart-breaking to know I will never hear his voice again. That I will never again hear his earth shattering sneezes. Doing this walk and raising money helped me feel slightly less useless. My Dad chose the route as it is one of his favourite spots. When we finished the walk some five hours later I felt emotional. It had been a beautiful walk, we’d laughed, talked but most of all completed the task I had set myself. Thanks Dad, you picked a beautiful walk.”

bake it! For MND: Cara Brown, nine, held a bake it! cake sale and raffle at her primary school in Jarrow in honour of her Grandad John, who is living with MND. Cara raised an amazing £315.
If you have something you would like to share with other members of our MND family, we would love to hear from you.

Letters, which must include your full address, can be sent to Your Voice, Thumb Print, PO Box 246, Northampton, NN1 2PR or via email at editor@mndassociation.org

Please note that letters may be edited. If your letter is printed we will send you an MND Association coin keyring.

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My mobility scooter

It’s come at last unpacking bit by bit.
I bustle around assembling my kit.
At last my mobility scooter in blue
Stands proud, shiny and brand spanking new.

The battery my son tells me now.
Is the heaviest bit and wow!
He’s not fibbing, certainly no joke.
As I push it to him - good bloke.

With battery charged and ready to deploy.
I’m raring to try out this fab new toy
With a twist of the key turn on LEDs
Red, amber and yellow not as big as peas.

Accelerator next, the exciting part.
I press down quick, I’m off with a start.
The air rushes past I’m going a lick
My son says “slow down you’re going too quick”.

“This is cool!” I shout with the wind in my face.
As I go downhill at a gathering pace.
Oops, I just missed a lampost better slow down.
My son comes up he’s wearing a frown.

How things have changed since he was small
He towers over me, he’s grown so tall.
He points to the tortoise and then the hare
I think he knows I haven’t a care!

Next I meet up with a friend in need
Of a scooter outing - Yes indeed!
We meet at Parke ready for fun.
My daughter, Alice, our minder has come.

We bounce downhill avoiding pebbles and nuts
Also a humpback bridge covered in ruts.
We make for a hill and get half way.
Then motors cut out and there we stay.

Friends afar

In previous editions of Thumb Print we asked you to take a photo of yourself on holiday with the magazine.

Alyson Adair and Gill Sherry first met when they took part in one of our cycling events in 2008. It was the loss of their respective father and father-in-law to MND that led them to sign up for the gruelling 275 mile ride and resulted in them becoming firm friends. Gill said: “We have much to thank the Association for and take comfort from the fact that a mutual experience of heartache and loss has resulted in a lifelong, unbreakable friendship.”

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MND simple thoughts

I sit about a lot as I’m totally dependent on my wife who has everything else to do beside my needs. I initially had difficulty sleeping and spent hours thinking negative thoughts.

Now when I get thoughts related to my MND journey, I write it down and it ends up as a poem.

I’m now at the stage where eye gaze is my only option for writing. My poems have taken hours and months to do but has significantly stopped negativity and made me very positive with MND.

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diary dates

- London Marathon: 23 April 2017
- Regional conferences: Liverpool: 6 May 2017
- London: 24 September 2017
- York: 11 November 2017
- MND Awareness Month: June
- Nightrider London: 10-11 June 2017
- Annual conference and AGM: 8 July 2017
- Newham 10k: 2 July 2017
- Silence Speaks: October 2017

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about us:

The Motor Neurone Disease (MND) Association
We improve care and support for people with MND, their families and carers, and fund and promote research that leads to new understanding and treatments. We also campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

As a charity we rely on voluntary donations. Our vision is a world free from MND.

Website
www.mndassociation.org

Social media
Online forum
A place for people affected by MND to share experiences and support each other.
http://forum.mndassociation.org

Facebook
www.facebook.com/mndassociation

Twitter
@mndassoc

MND Connect
Our MND Connect helpline offers advice, practical and emotional support and signposting to other organisations.
Open Monday to Friday 9am to 5pm and 7pm to 10.30pm.

0808 8026262
mndconnect@mndassociation.org

get involved:
telephone: 01604 250505
website: www.mndassociation.org
e-mail: enquiries@mndassociation.org

My theory of everything MND

I was diagnosed with Primary Lateral Sclerosis (the slower progressing form of MND) in May 2013. My wife and I attend the Second Thursday Group of the Nottingham Branch. It’s a great place to be, to mix and mingle and share thoughts and ideas with other members. We were recently invited to write a poem about MND, so with my silly sense of imagination and humour and the ongoing trials to find a cause for MND I came up with this:

What is it about MND?

I am not normally someone for poems, but there is something special about the MND community.

Reading Thumb Print you can’t help but be amazed at the numbers of people who give up their time to help us.

These are my thoughts on motor neurone disease,
That’s MND to you and me,
There is no cure and the cause is unknown,
But I have a theory I worked out on my own.

In the middle of the night an alien spaceship appears within sight,
It hovers for a while then it beams me up from my bed,
And into the spaceship which is coloured red.

Aboard the spaceship Uranus bound,
The little green aliens don’t make a sound,
They have some breakfast and a cuppa too,
While they look me over and decide what to do.

Lying face up on a bed of slate,
They induce me into a hypnotic like state,
Then one by one they prod and poke,
I start to cough and begin to choke.

A pipe placed here and a tube put there,
And the little green aliens are climbing into my ear,
They open my mouth and inspect my teeth,
I start to gasp and struggle to breathe.

The little green aliens have no respect or care
As they remove my pyjamas and leave me totally bare,
They have a good laugh then put me in a bath of alien bleach,
I begin to mumble and lose my speech.

Regarding my mobility the aliens are to blame,
They mixed up the neurones that connect to my brain,
Now I can hardly walk and get cramps in my arms
That gives me some pain.

On the return from Uranus to earth,
The little green aliens have their supper and another cuppa,
They hover for a while then beam me down back into my bed,
From their spaceship coloured red.

But my theory of MND lies with these little green brats,
Little green aliens abduct us for sure,
Doing their tests and so much more,
I’m absolutely certain they cause MND.
Do you have a theory or do you agree?

Paul Wilkinson, via email

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They swim, they walk and they run
Holding concerts to help everyone
With cash for this awful condition
For the search for a cure has begun

I don’t want to be a “who sadly”
So much still remains to be done
To enjoy life with friends and with family
Visiting places I haven’t yet gone

My arms aren’t as strong as they should be
And walking’s a bit of a strain
But we have to go on and on trying
To get on that cruise ship again

I don’t want to be a “who sadly”
But one day it might just be me
Perhaps then people will write nice things
Of my battle with cruel MND

So thanks to all the researchers
The volunteers who are helping so much
I want you to know I appreciate
Your running and walking and such

So I have to keep reading my Thumb Print
To see all the work that’s being tried
Finding answers to this terrible problem
So fewer will sadly have died

Philip Brindle, via email
Grid Pad

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thinkSmartbox.com/thumbprint