



# NEWSLETTER



THE SKY'S THE LIMIT!

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## Canoe challenge 2019

It was an early start on the Saturday of the last bank holiday weekend in May.

Eight brave people set off from Northampton on the river Nene with an incredible 69 miles and 39 locks to negotiate in three days. The weather was brilliant that Saturday and the back-up car went to the first meet point whilst the set up crew went off to the first night's campsite. Shock horror, a phone call from the team, one of them was sinking and having to bail out his kayak.

The set-up crew was summoned to the first meet and they carried a canoe some 400 yards to the lock near Billing. Upon arrival of the team our ex-Seal team/Marine member Adam Cunnington, owned up to not checking his rear bung which was allowing water to enter. Lesson learnt they all set off for the middle Nene yacht club and fish and chips for tea. After a great stay at the yacht club and a hearty breakfast, I can highly recommend this place if you sail or want to learn to sail, so friendly and cheap yearly membership.

Day two started with our only unexpected Eskimo role, well Leo Amies fell out of his kayak so we had a ten minute wait whilst it emptied. The team set off for the hardest part of the challenge to Yarwell Mill. The weather on day two was awful with heavy rain and the odd thunderstorm. Again big thanks go to Yarwell Mill for letting us pitch up and use their facilities for free. The team made good time and arrived in plenty of time to shower and rest before we had beef stew and bread which was yummy.

The third day was the easiest for locks, only four but was a long slog as the team had long distances to paddle. But they made great time and finished in good time on the bank holiday Monday.

So big thanks to the teams Russell Huber, David Croke, Leo Amies, Adam Cunnington, Katie Marshall, Jacqui Allen and Isaac Allen.

Also huge thanks to Mick Huber and Malcolm Clifford for their help with the event.

Thanks also go to John Miller from Proteus canoe club who taught the team to paddle in a straight line and to the Peterborough Sea Cadets who let us loose on their kayaks with their life vests and paddles.

*I seem to have sprung a leak!*



## The sky's the limit!

Jumping out of a plane from thousands of feet would be a daunting prospect for most of us. Well, no one seems to have told Maz Hunnable, who wasn't going to let living with MND get in the way of an airborne adventure. Here's what she had to say about it...

"My sky dive was amazing. The red devils treated me like royalty - they were so caring. I was worried about my legs being taped together, but understood it had to be done. It worked really well and Nathan who I jumped with was fantastic with the help he gave me.

I had so many family members there to support me and 4 of them also did the jump. So far I have raised almost 5 grand and I'm really pleased with the amount."





## Fundraising for the MNDA by Brown & Co, Property & Business Consultants LLP

Having been diagnosed with MND in March this year, I was extremely pleased that from a personal point of view my fellow partners in Brown and Co chose the MNDA as their charity for the current year of 2019.

Various events across the regional offices have taken place so far but more locally the Huntingdon office decided to organise a charity walk around the perimeter of Grafham Water totalling 9.2 miles. This took place on Sunday, 22<sup>nd</sup> September with a fantastic turnout and show of support from friends, colleagues and clients alike numbering some 200 in total. Donations were also kindly received from many parties who were unable to participate on the day; the total raised so far for the walk alone has now reached an astounding £24,500 with monies still coming in.

I am proud to announce that Brown and Co so far has managed to raise a grand total of over £45,000 from all the activities undertaken to date. Throughout the rest of the year, further events are taking place; a timed online auction was very successful featuring varied and unusual lots from experiences and holiday breaks to season tickets and memorabilia. The sum of bids for the auction alone at present totals approximately £21,000.

I am truly humbled by the generosity of everyone and looking forward to seeing what our continued efforts can bring.

**Chris Purllant**

**MNDA member living with MND**



## Lyke Wake Walk 21st July 2019

In support of Motor Neurone Disease for research and the local Cambridgeshire group a team of four first time Lyke Wake Walk (LWW) attempts met with success both on the crossing and in fundraising where over £3,330 was raised for MND. There was an unsuccessful walker we also supported and despite failure at the start of Wheeldale, he raised £550 for the Addenbrookes Kidney Patients Association.

They all set off together in the morning light at 04.57 at the LWW stone at Cod Beck and exactly 15 hours later they got to the finish stone at the end of Stony Marl Moor and Beacon Howe at 19.57.

Times for the sections were only notable as they got impetus near the end and flew across Fylingdales in under 2hours 30 mins. The weather was beautiful all day and the surfaces were dry for the most part. All the participants were first time walkers on the LWW and ranged in age from 59 to 69 – none of them had ever walked more than 30 miles before, so it was a great achievement.

Completers were: Carol Deytrikh-White; John White; Jonathan Stafford; Tim Bryson.

### Andrew Norton: Cottenham Fundraising Group for MND



## 40th Anniversary Service at Peterborough Cathedral

The Cambridgeshire Branch held an Anniversary Service at Peterborough Cathedral on Saturday 5th October to commemorate 40 years since the start of the Motor Neurone Disease Association and to remember those we have lost to this disease.

The service was organised by Simon Crooke in collaboration with Canon Dr Rowan Williams, Precentor at Peterborough Cathedral. It was attended by three local Mayors: the Mayor and Mayoress of Huntingdon, Councillor and Mrs Stephen McAdam; the Mayor of Whittlesey, Councillor Mrs Julie Windle and her consort, Mr Robert Windle; and the Mayor of Wisbech, Councillor Michael Hill. We received apologies from the Deputy Lord Lieutenant, Karim Khalil, QC, who had a family crisis at the last minute.



The Gildenburgh Choir directed by Celia Johns, sang two items: 'You will always need a time for reflection', words and music by Alan Simmons, and 'When I am down and oh, my soul's so weary... You raise me up, so I can stand on mountains...', words and music by Brendan Graham and Rolf Lovland. Both were sung beautifully and were very touching.

During the service three appropriate hymns were sung with Val Kay, a carer to her husband Paul, reading from Psalm 46 'God is our refuge and strength'. Our grateful thanks to Val for volunteering to read for us. There was a poem read by Sue Hallifax, our Association Visitor: 'You can shed tears that they are gone, or you can smile because they have lived'; a further Bible reading from St John's Gospel, the story of Lazarus of Bethany by our Branch Chair, Cynthia George. The service finished with Prayers from different religious traditions followed by the hymn, 'We would be one as now we join in singing... We would be one in building for tomorrow... We would be one in living for each other...', and a Blessing.

The service was followed by a delicious buffet where everyone could chat with old and new friends. We were delighted to see many old friends and many of those who regularly attend our Get-togethers and that they were able to join the Committee and Association Visitors to make this a special and memorable day.

Last but not least, we are very grateful to Simon Crooke, our Branch Fundraising Coordinator who not only organised this whole event in the midst of his own family bereavement, but also expressed his own personal reflection having lost his wife, Susan, to this disease several years ago. He said he has much confidence in the research being undertaken throughout the world. His great hope is that there will be a cure for MND long before the 50th Anniversary of the Association.

**Maire Collins, Branch Secretary**

**Veronica Angus, Committee member**

**Cynthia George, Branch Chair**



## Musical fundraising for MNDA and the Peterborough Cancer Wellbeing Centre Garden

Just under three years ago there was a romantic and musical coming together of John and Sue. Sue a member of Cambridge Rock Choir and John a singer, guitarist and former front man of Peterborough bands: The Collaborators, Shades of Green and Accord 3. Their lives and their music began and continue to gel harmoniously.

Sue has been an Association Visitor for the Motor Neurone Disease Association following the death of her husband with MND in 2009. John is now a volunteer at the Cancer Wellbeing Centre in Peterborough having fortunately won his own battle when he was diagnosed with oesophageal cancer 4 months after he and Sue met!

Music became a very important part of their relationship and they decided to sing at various events raising money and hopefully, spirits. They have now played over twenty gigs including the last three July MND fundraising Garden Parties held in Pam Wilkie's lovely garden in Hail Weston near St Neots.



Sue and John sing and play their brand of popular hits from the 50s to today at functions and events, in cafes and restaurants and outdoors in warmer weather! The photo is when they played on a sunny Saturday morning a few weeks ago at the MD Coffee shop in Peterborough.

They will be playing there again. The coffee there is excellent and the lunches tasty and it would be lovely for people to pop in and support MNDA. You will get a warm welcome from John and Sue and the café owners Masoud and Deborah.

They have recently decided to call themselves 'SIMPLY2' and can be contacted for bookings via John 07986 795773 or by email [collab1@icloud.com](mailto:collab1@icloud.com). They perform free of charge at MND and Wellbeing Centre events. For other events they charge a small fee which is split between the two charities with a small amount taken for equipment expenses.

They look forward to seeing you at the Christmas get together at Scotsdales on Thursday December 5<sup>th</sup>.

## Melanie White

### 15 Year's Long Service Award

The MND Association likes to recognise long service and awards volunteers for their loyalty in the work they undertake on behalf of the Association. Mel, our Branch Treasurer, has been keeping our branch finances in order and in the way the Association requires for many years. She has her family life as well as working but somehow manages to devote many hours to keeping our accounts as detailed and accurate as needed.

Mel was unable to come to our branch AGM in March this year which is when these awards are normally presented so the opportunity was taken at a recent branch committee meeting to present her 15 year's awards badge and certificate to her. The committee passed on its grateful thanks to her for all her hard work over this time.

## Cynthia George



## The Independent Living Services at Cambridge City Council's Sheltered Housing Schemes

We were nominated by The Independent Living Services in Cambridge as their charity of the year. On 1<sup>st</sup> July I was asked to go along to their premises in Mill Road when I was handed a cheque for £439.70. I gave a short talk about MND and answered a

number of questions.

This was a fantastic sum to receive and I thanked them for their generosity .

## Cynthia George



**2 residents of Ditchburn Place Residential Home presenting the cheque to Cynthia George**



## **Social Afternoon Gatherings**

**Thursday 4<sup>th</sup> July at**

**David Rayner Centre,**

**Scotsdales, Great Shelford, Cambridge**

An exceptional number of members came along for this afternoon. It was a lovely hot sunny day which may have encouraged lots to come out.

We had a talk and demonstration from Helen Grace, Regional Sales Manager at Abilia, on the new SL50 Lightwriter. The Lightwriter, as many of you will know, is a text-to-speech device for those who cannot communicate effectively through speech. The latest model has some new features – technology never stands-still!

**Wednesday 11<sup>th</sup> September at**

**Hemingford Abbots Village Hall**

We had a good afternoon at this lovely, bright and spacious venue. The hall is easily accessible, has excellent facilities and parking.

Lots of chatting and it's surprising what subjects get aired as well as the helpful tips passed on between members.

**Thursday 3<sup>rd</sup> October at**

**David Rayner Centre,**

**Scotsdales, Great Shelford, Cambridge**

We were back at this popular centre for our October social afternoon. We welcomed 'old' and 'new' friends and had a lively and entertaining event.

Our speaker was Martin Hanson of LPA MadeSimple who talked about Lasting Power of Attorney.

Heidi Allen, Member of Parliament for South Cambridgeshire, also joined us during the afternoon. She chatted and mingled and stayed on for quite some time. I am sure she will have gained a great deal of knowledge about MND from talking with many of you.

**Cynthia George**

Register at [cambridge@mdassociation.org](mailto:cambridge@mdassociation.org)

# CYCLE CHALLENGE 2020

6TH SEPTEMBER

OXFORD TO CAMBRIDGE

# mda

motor neurone disease  
association



## *Mysteries, Yes*

Truly, we live with mysteries too marvelous  
to be understood.

How grass can be nourishing in the  
mouths of the lambs.

How rivers and stones are forever  
in allegiance with gravity  
while we ourselves dream of rising.

How two hands touch and the bonds  
will never be broken.

How people come, from delight or the  
scars of damage,  
to the comfort of a poem.

Let me keep my distance, always, from those  
who think they have the answers.

Let me keep company always with those who say  
"Look!" and laugh in astonishment,  
and bow their heads.

—Mary Oliver



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To find out more about the Cambridgeshire Branch visit

[www.mndassociation.org/cambridgeshire](http://www.mndassociation.org/cambridgeshire)

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### Dates of Get-Togethers in 2019

Thurs 5th Dec      Cambridge

### Get-Togethers early 2020

Weds 15th Jan      Hemingford Abbots

Thurs 13th Feb      Great Shelford, Cambridge