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40TH
YEAR



The Cambridgeshire branch of the MND Association presents a multi-faith commemorative service and reception at Peterborough Cathedral to celebrate forty years of the Association on Saturday 5th October 2019. The service starts at 4pm.



The service is free but there is a small charge of £10 per head for the reception, which includes a buffet and hot drinks. All tickets must be booked in advance and booking forms are available from:

cambridge@mndassociation.org

* Please note the corrected date for this service on Saturday 5th October 2019.



Change of Email for Branch Secretary

To enable others to be able to access messages during holiday/illness, etc. I have opened a new email address for the Branch: secretarycambsmnda@gmail.com.

It would be helpful if all those who have my personal yahoo address would kindly delete it with immediate effect and use the new one.

Thank you.

Maire Collins: Branch Secretary

Social Afternoon Get Togethers

Wednesday 14th November

Peterborough Salvation Army Centre

Our venue for the northern part of the county. Our gatherings are quite small here but always lively. The weather was mild and dry and this time more of you came along so this made for a very pleasant afternoon.

With a number of the committee and members present, there was plenty of chatter and catching-up. Cups of tea were served and savoury and sweet snacks were enjoyed.

Thursday 6th December

David Rayner Centre, Scotsdales Garden Centre, Cambridge

December Christmas "Special"!

How lovely to see so many of you for this Christmas-themed afternoon which brings to an end another year of our social afternoons.

Warm non-alcoholic mulled punch gave the afternoon a spirited start which continued all afternoon. The tables

were laid out with lots of festive goodies with crackers being pulled and party poppers exploding. At the same time we had Sue Hallifax, one of our Association Visitors, and her partner John entertaining us with their singing and guitar playing. Some familiar Christmas carols brought out our singing voices.

There was a quiz set by Geoff and Chris Glover, which everyone was very competitive about with a prize for the winner.

Savoury nibbles, mince pies, Christmas cake and a home-made chocolate gateau were enjoyed along with tea and coffee and of course more of the mulled punch.

The afternoon drew to a reluctant close with a special "mystery" gift for each of our inspiring and lovely members living with MND, along with a bright and cheerful poinsettia.

Personally, I find this a very uplifting afternoon; it is to me a chance in a very small way for your local branch committee, hopefully, to put on an extra special afternoon at this particular time of the year in a light hearted atmosphere.



Wednesday 9th January 2019
Hemingford Abbots Village Hall

Our first social afternoon at this venue although for some not the first visit as we now hold our Branch AGM here. Access is very easy from the A14 and the hall has its own car park. The building is light and airy with full length glass doors opening out on to a garden area.

We had a small gathering which allowed plenty of conversation – it is surprising the subjects covered and what we can each learn from each other.

Plenty of tea and coffee was available along with the usual other goodies.

This is, I feel, an ideal venue for our social afternoon gatherings and am hopeful many more of you will come along when we return there in September.

Thursday 7th February
David Rayner Centre, Scotsdales Garden Centre, Cambridge

This was another well attended afternoon at this popular venue. The weather for this time of year was exceptional, which always helps.

We were joined by two National Office staff, Nick Goldup, Director of Care Improvement at the Association, and John Gillies-Wilkes, Regional Development Manager for the East.

Nick gave an interesting talk on his role within the Association since he joined eighteen months ago. He had

previously enjoyed a successful corporate career for a number of years, is a member of the National Wheelchair Alliance and has worked for Whizz-Kidz, so has a healthcare improvement background.

From the last survey undertaken by the Association he said 88% of people who responded were highly satisfied with the service the Association provides. He mentioned there had needed to be a change in the riser/recliner chair policy as the cost of cleaning/refurbishing these chairs was now too great and unsustainable. The procedure for obtaining a grant towards one of these chairs will still need the assessment by a Health & Social Care Professional to ensure suitability; a quotation can be obtained from Accora which will need to be submitted via the H&SCP to Support Services along with a Support (Care) Grant application form. Nick said the change will allow the Association to continue to support people living with MND to receive this important piece of equipment.

On a positive note he said he felt the Association has a great team of volunteers and staff. He summarised his talk by saying there will be challenging times ahead in the healthcare environment with more and more people needing support and then answered questions from the floor.

Nick and John both mingled and talked to many of you while we brought round tea and coffee along with biscuits and other “bits and pieces”.

They have both said they always learn a lot from coming out and meeting

members at events such as our social afternoons. Thanks to you all for your support and hope you feel these events are informative, interesting and above all an excellent way of meeting others in a similar situation.

The afternoon went quickly and soon it was time to leave to get home.

2019 Get Togethers

As you will no doubt have seen from the 2019 Events Diary and our last newsletter, we have four venues throughout the county this year where we will be holding our social afternoon gatherings:

Cambridge

David Rayner Centre

Ely

Larkfield Resource Centre/Ely

Community Centre

Huntingdon

Hemingford Abbots Village Hall

Peterborough

Salvation Army Centre

We realise the county of Cambridgeshire is fairly wide-spread and by having these four venues we are hoping this will give easy access and closer locations for many of you to get to these centres.

These afternoons are run for you as members to come along and meet others, have a chat over a cup of tea and have a relaxing afternoon. Family members, carer, or friends are welcome to come with you. We can help with the cost of transport by arranging taxis (wheelchair friendly if needed).

Do come and join us – we are a friendly group. You will be made very welcome.

Cynthia George

Tel: 01954 202095/07515 534430

Email: c.i.george@icloud.com

2019 Cambridgeshire Branch AGM

Maire Collins, Branch Secretary, has now sent out the information pack for this year's Branch AGM which will be held on Wednesday 27th March, 12.30pm at Hemingford Abbots Village Hall.

If you would like to join us for this event and have not had details, or indeed have received the documentation and not yet replied, then please get in touch with Maire:

Email:

secretarycambsmnda@gmail.com or

telephone: 01954 200873

Chris Glover retires from branch committee

Chris retired from the committee in December 2018 after 17 years' service, but she will still maintain her valuable Association Visitor duties. She will attend Get-togethers and other events so we are very pleased that she will not be losing touch.



Chris and Geoff are pictured at their home after the last meeting. They hosted a delicious lunch for the committee members who had thanked them very much for all their hard work over many years.

Veronica Angus, Committee Member

Fundraising

Mr Billy Maher from the NISA store in Gunthorpe, Peterborough has raised £1000 for the branch.

Also, Mr Joe Gilbert is embarking on an ultra-marathon in Scotland by running 52 miles in under 16hrs.

In December we had a stall at Tesco, Bar Hill. It was a great day selling various items made by the Cottenham Fundraising Group and raised a great total of £447.50

The canoe challenge is coming on well and should be a great weekend. There is still time if you would like to join in. We would like to thank the Middle Nene Yacht club and Yarwell Mill for helping us out with overnight camp sites.

The 40th Anniversary cathedral service at Peterborough Cathedral is progressing well. Please email Cambridge@mndassociation.org to book your tickets.

Strawberry Tea

Pam Wilkie will be hosting another Strawberry Tea and Musical afternoon in the garden of The Old Post Office, Hail Weston, St Neots on the afternoon of Sunday July 21st.

We would love to see as many of our members and friends as possible at this relaxed social afternoon, enabling us to raise some money for the Cambridgeshire Branch.

Please put this date in your diary!

Easyfundraising.org

Easyfundraising.org is a great way to raise money just by shopping online. You don't pay anything extra. All you need to do is go to the easyfundraising website, click through to the retailer you want to buy from and make your purchase.

The price will be exactly the same and the retailer will give you a cash reward that you can turn into a donation. Easyfundraising collect this and send it on at no extra cost.

Visit easyfundraising.org and find out more.

Are you fundraising for MND?

If you or a friend are thinking of fundraising to help the MNDA to help others, then please let your local branch know.

We as a branch can assist with giving a short speech or getting you promotional posters and flyers. We can also help to get you T-shirts for your helpers and to also point you in the direction of your press offices.

To contact us: either email Simon Crooke on:
cambridge@mndassociation.org
or the branch secretary on:
secretarycambsmnda@gmail.com

Ploughing on!

The Peterborough Farm Machinery Preservation Society held a ploughing day and raised £2060 for the branch. A great day was had by all and the cheque was handed over at a meeting of the group at Childers in Whittlesey.

In the top photo are two steam ploughing engines. The bottom picture shows two Marshall Combine Harvesters. The orange one is unique as it is the only surviving self-propelled combine harvester.

It was of an unusual design as it had two engines. One to drive the cutting and threshing mechanism and the other to drive the road wheels. This has been fully restored by Brian Knight and his father Ron Knight (you might like to Google him). They have one of the largest collections of vintage combine harvesters in the country!

Simon Croke

CAKES, COFFEE & West Lodge Pottery

Friday 5th April 10.30am-1pm
in aid of
Motor Neurone Disease Association



at
41 Cage Hill, Swaffham Prior
POTTERY, CAKE STALL, RAFFLE
Contact: Margaret 01638 744390



Ralph Barker, Simon Croke & Brian Knight



The Lyke Wake Walk – 6th July 2019



The classic *Lyke Wake Walk* starts at the LWW Stone on the roadside by the public car park at the Old Quarries, 1 mile north of Osmotherley. The total distance is around 40 miles and there is about 4000ft of ascent! It finishes at the trig point and LWW stone above the sea at Ravenscar.

This is one of the most challenging and famous walks in the UK. A local farmer, Bill Cowley, started the walk in 1955. He and a group of friends set out to walk across the whole of the North York Moors National Park by the highest and most direct route in 24 hours. He did not realise what he had started!

The walk was named the 'Lyke Wake Walk' and has a coffin-shaped badge commemorating the many ancient burials which took place on the moor - these burials are the tumuli or 'howes' seen on the map. Over the intervening years, a huge number of crossings were made (over 100,000 and rising!) The New Lyke Wake Club was created after the death of Bill Cowley to continue to support this walk, which has become famous as one of *the* open challenges for long-distance walkers to have under their belt.

The coveted badge is recognised as a symbol of a fine achievement all over the UK and beyond. Membership of the club is only through a documented and reported crossing within 24 hours and they issue memorabilia including a 'condolences on your walk' card with dates and times of your crossing, badges, ties, car stickers, T-shirts etc. The support for this walk is quite a tough ordeal too, and even supporters are entitled to a special commemorative badge! We will ensure that all our finishers are members and will report these successful crossings. The club supports this and issues awards for repeated crossings! Social events and a race are held annually. The record time for the race (fell-runners) is well under 5 hours! (So just enjoy it and walk at a sensible pace).

Our event for 'Walk to D'Feet'™ MND will follow the traditional route, and we will have 6 support points. It will be well organised and supported. Completing this event will be a serious personal challenge as it is 40 miles of mixed walking, as far from civilisation as it gets in most parts of England.

It will be a rewarding day for all the finishers. The scenery along the route is beautiful and there are a few bogs to contend with, although plenty of

steep ups and downs on firm tracks or moorland paths. It is not intended as a race, but as a personal challenge event for all to test their ability and endurance over the course and enjoy the atmosphere of a friendly day out on the hills, whilst raising money for a very good cause.

Fast walkers could finish in 13 hours. Normal walkers should aim for 16 hours, which is the suggested time, but we will support finishers up to 17 hours if they are fit enough to finish the last section at the final support point!

You are quite far from a road or habitation on this walk and it can seem quite wild on the top of the moors in some places, so proper walking gear and preparation is essential. The walk reaches the highest point on the North York Moors - Round Hill / Botton Head at 1489ft / 454 m altitude. It crosses the moors at their highest and widest point. We are choosing the time of year with the



longest available daylight, but everyone **MUST** have a torch/headlamp and spare batteries in case you are approaching dusk at the finish. The weather can turn unpleasant very fast in this area, so maps, compasses and survival gear are essential. We will issue a walking guide to the route. There is also a very good book published by the club which gives a lot of information about the route and the walk in general. The website for the club is excellent too at: <http://lykewake.org>

Entries: There is a **non-refundable entry fee of £30 per person**. This covers costs for Minibus support, T-shirt, food, Public Liability Insurance and bottled water for the walk and includes your nice warm bacon roll at Checkpoint 2! Sponsor forms will be available on receipt of your completed entry.

For full details and entry forms email andrew.j.norton@pdmassociates.co.uk.



On 24th January we launched Michael's story, a video showing why our Scrap 6 Months campaign is so important for people with MND and their families.

We are proud to be working alongside Marie Curie on this campaign. Together our petition has been signed by 8,000 supporters. Thank you to everyone who has signed the petition so far and shared through your online and offline networks with your family, friends, work colleagues and neighbours. Please continue to sign, and share it. The more signatures on the petition the stronger our voice will be! Sign online at <https://e-activist.com/page/33936/petition/1>.

You can also download a printable version from our website and either scan or email to tina.downs@mndassociation.org or return by post for the attention of Tina Downs, MND Association, David Niven House, 10-15 Notre Dame Mews, Northampton, NN1 2BG.

Helen Riley

Local Campaigns Co-Ordinator East
Motor Neurone Disease Association
Mobile: 07733893108
Email: helen.riley@mndassociation.org

MNDA CHARTER Cambridgeshire County Council

It was all down to the excellent work by Fred Smith, one of our Association Visitors, that in the last edition we were able to let you know Cambridgeshire County Council were adopting our Charter. The picture shows the officials signing the document along with Fred Smith and Cynthia George from Cambridgeshire Branch.



This now means we have two councils on board as Peterborough has already adopted the Charter.

In an ideal world it would be excellent to get all the other councils in Cambridgeshire to adopt our Charter. If any enthusiastic person would like to get involved to get the word spread to other councils then please get in touch. We can offer help and guidance to take this forward.

Cynthia George

01954 202095/07515 534430

Taxi Card Scheme

If you are disabled, on a low income and live in the Cambridge City Council area, the Taxicard Scheme can help you pay for taxi journeys.

When you join, you'll be given 100 vouchers per year, each entitling you to £3.50 off your fare.

Vouchers can only be used on fares of £4.50 or more, which means you must pay at least £1 towards the fare. You must show the driver your voucher before starting your journey.

Each book of vouchers is valid from 1 April to 31 March of the following year. If you join the scheme after 1 April you will be issued a proportionate amount of vouchers for the remainder of the year. You will be contacted before April each year to confirm your continued eligibility for a Taxicard.

You can find an application form and more information online at www.cambridge.gov.uk/media/3253/taxicard-application.pdf

To join the Taxicard scheme you must receive one or more of the following benefits:

- Income Support
- Pension Credit
- Income-based Jobseekers Allowance
- Housing Benefit
- Universal Credit
- Council Tax Reduction, including disability premiums or reductions but not including the

25 per cent single occupancy reduction

- Income-related Employment and Support Allowance (Not contribution-based ESA.)

You should also receive at least one of the following:

- The higher mobility component of the Disability Living Allowance
- Mobility Enhanced Personal Independence Payment
- Attendance Allowance
- War pensioners' mobility supplement
- Be registered blind or partially sighted.

If you don't receive any of the secondary allowances you're still eligible for a taxicard if you're unable to use public transport because:

- You're a permanent wheelchair user
- You can't walk without a walking aid such as a frame/crutches etc.
- You can't walk more than 100 metres
- You're unable to stand unsupported for more than 5 minutes.

A Report by Fred Smith, Association Visitor on his trip to Adelaide, Australia, 23 November 2018

I paid a visit to Motor Neurone Disease Association, South Australia, (MND SA) where I met the CEO, Karen, and had a good chat with Jerry, the Client Support Advisor & Manager. Jerry's role seems to be much in line with our RCDA role and his colleague, Ash, also present at the time, seems to be like our CSN.

We chatted about many things and to my mind what came out was that, although we are at opposite sides of the world, our respective associations are running parallel in our desire to look after plw MND and wanting a cure.

MND SA currently have approximately 130 plw MND whom they support, however Jerry feels there are many more who have not been referred or who have just not bothered to contact them. In the past year (July 2017 - June 2018) there have been 670 MND Advisor face to face visits.

The small team at MND SA also organised a very successful MND Australia National Conference during August which lasted over two days. This involved a coming together of the associations of all the other states within Australia as well as MND Australia. The representatives of each of the states had the chance to give an update on their organisation along with any challenges they are facing. There were also talks by individuals on various subjects. Later there was a fun element where delegates were given the opportunity to be creative including decorating tables with props, and prizes were given to the most creative table and individual.

Something which I was drawn to was 'Come Walking, Get Talking Carers Group', which is about supporting the carers, friends and family of plwMND. It comprises of a walk of around 2km and up to an hour's duration. As the title suggests it enables carers, etc. to have a bit of exercise both physical and of the jaw!

Whilst in the office, I left several back copies of Thumbprint and a couple of copies of our Cambridgeshire newsletter in order that they

can see what we in the UK are doing and perhaps give them an idea for future fundraising for MND SA.

I had no plans to meet up with the team again on this visit to Australia as I could see they were quite busy with meetings, etc. - sound familiar to you all???

Fred Smith, Association Visitor

New MND Clinic at City Hospital Peterborough

After many years of discussions we have now established a dedicated MND Clinic in City Hospital Peterborough. We have been concerned about people in the north of the county struggling to get to Cambridge to the Care Centre and have wanted to improve the MND provision in the Peterborough area.

The new clinic is led by the neurologist Dr Baumer who also works at the Cambridge Care Centre and has a particular interest in MND. At the clinic patients will not only have an appointment with him but will have the opportunity to chat with Brenda Parkes (CSN) or myself. We hopefully can give information and ensure that the correct referrals are made to local services. Whilst the clinic will not at this stage be multi-disciplinary both Brenda and I are linked into the local Neuro teams and can ensure the multi-disciplinary teams are involved with the patient appropriately. The challenge for the clinic is that we are also seeing patients from surrounding areas such as Lincolnshire, Northamptonshire and Rutland so we are having to learn about services in those areas as well.

We are hoping that the clinics will continue to develop this year and improve the hospital experience for people living with MND in the area.

Lindsay Goward

Regional Care Development Adviser for East Anglia

Motor Neurone Disease Association

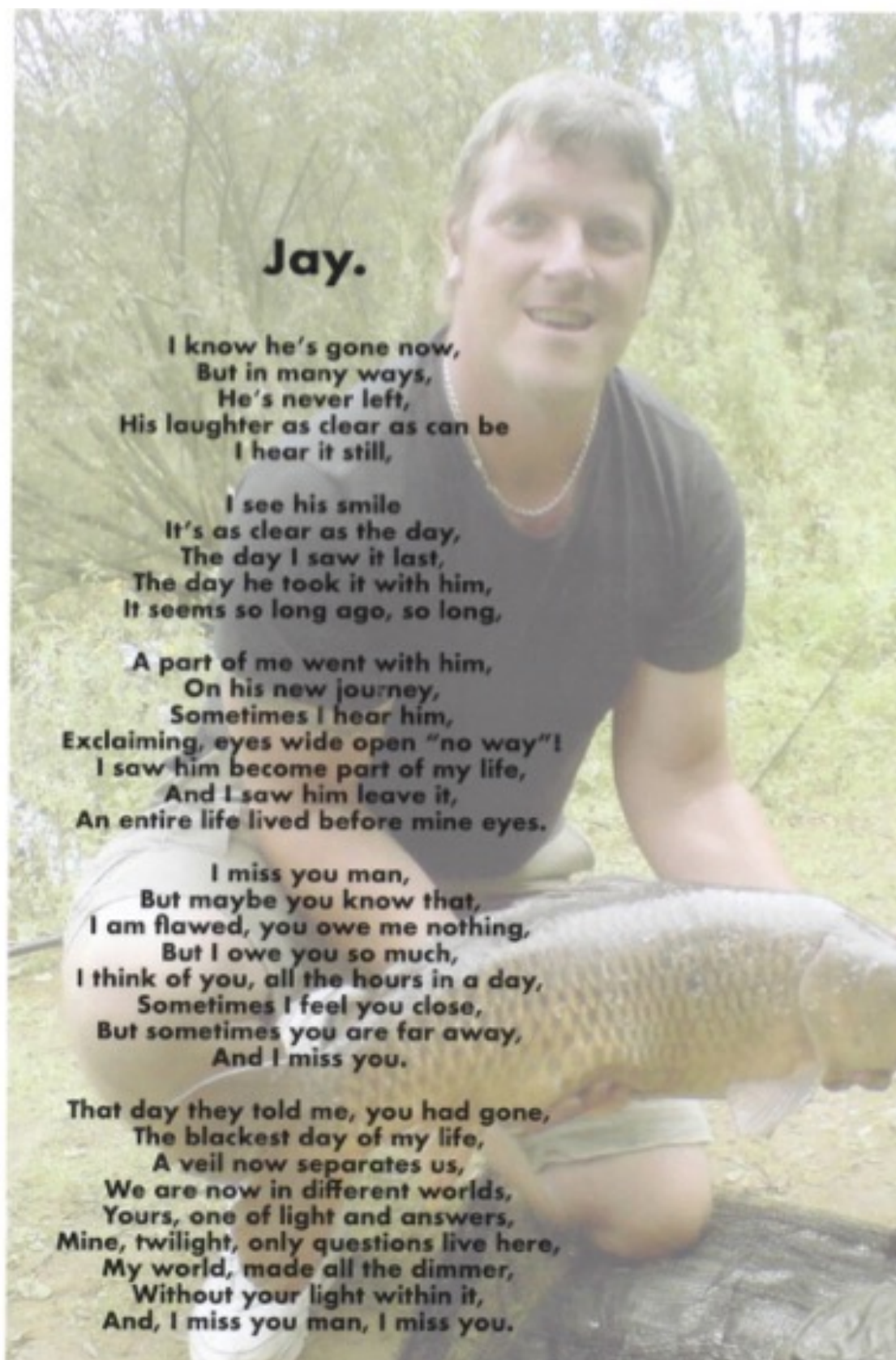
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Jason Newman

1973-2013. This poem was written by Jay's brother Neil.



Jay.

I know he's gone now,
But in many ways,
He's never left,
His laughter as clear as can be
I hear it still,

I see his smile
It's as clear as the day,
The day I saw it last,
The day he took it with him,
It seems so long ago, so long,

A part of me went with him,
On his new journey,
Sometimes I hear him,
Exclaiming, eyes wide open "no way"!
I saw him become part of my life,
And I saw him leave it,
An entire life lived before mine eyes.

I miss you man,
But maybe you know that,
I am flawed, you owe me nothing,
But I owe you so much,
I think of you, all the hours in a day,
Sometimes I feel you close,
But sometimes you are far away,
And I miss you.

That day they told me, you had gone,
The blackest day of my life,
A veil now separates us,
We are now in different worlds,
Yours, one of light and answers,
Mine, twilight, only questions live here,
My world, made all the dimmer,
Without your light within it,
And, I miss you man, I miss you.

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Northampton

NN1 2BG

Registered charity number 294354

Find out more about the Cambridgeshire
Branch visit

www.mndassociation.org/cambridgeshire

www.facebook.com/cambridgegshireMNDA

Dates of Get-Togethers in 2019

Weds 3 rd April	Peterborough
Thurs 2 nd May	Cambridge
Weds 5 th June	Ely
Thurs 4 th July	Cambridge
Weds 11 th Sept	Hemingford Abbots
Thurs 3 rd Oct	Cambridge
Weds 6 th Nov	Ely
Thurs 5 th Dec	Cambridge